DOCUMENT RESUME

ED 422 958 IR 057 158

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TITLE Development and Implementation of a Pediatric Resource Library in a Pediatric Department.
PUB DATE 1997-00-00
NOTE 187p.; Ed.D. Practicum, Nova Southeastern University.
PUB TYPE Dissertations/Theses - Practicum Papers (043)
EDRS PRICE MF01/PC08 Plus Postage.
DESCRIPTORS Access to Information; *Child Caregivers; Children; *Disabilities; *Information Services; *Information Sources; *Library Development; Medical Libraries; Medical Research; User Needs (Information)

ABSTRACT

Raising a child with a disability requires an even greater amount of information than that needed to raise a "typical" child. This information is not as easily accessed as information regarding typically developing children. Parents require this information to help promote their child's development, learn information about diagnoses and treatment options, discover national and local resources, make informed decisions and be better advocates for their child. A resource library was designed and implemented in the therapy area of a rehabilitation hospital. The resource library provided a variety of information relevant to the care of a special needs child, including funding, diagnoses and national and community resources. Caregivers responded positively to the resource library. They found it convenient, helpful and filled with relevant information. Staff responded positively as well, as information was readily available to them, and when indicated, they were able to suggest that parents access more detailed information in the resource library. Caregivers improved in their fund of information and confidence levels in regards to caring for their disabled child after the implementation phase. Parents have requested that the resource library expand its features. (Appendices contain staff questionnaire on parent information, resource assessment, memo to hospital departments, cover letter, information assessments in English and Spanish, library index, figures and tables, as well as photocopy request forms.) (AEF)

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ED 422 958

Running head: DEVELOPMENT OF A PEDIATRIC LIBRARY

Development and Implementation of a Pediatric Resource Library in a Pediatric Department

by

Helene Thau

Cohort 14F

A Practicum Report Presented to the
Master's Program in Life Span Care and Administration
in Partial Fulfillment of the Requirements
for the Degree of Master of Science

Nova Southeastern University

1997

IR057158

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11/26/97

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Abstract

Development and implementation of a pediatric resource library in a rehabilitation hospital. Thau, Helene A., 1997: Practicum Report, Nova Southeastern University, Master's Program in Life Span Care and Administration. Descriptors: Parent Education/ Disability/ Resource Center/ Parent Competence/ Resource Library/ Hospital Library/ Parent Resource Center/ Parent Participation/ Parenting/ Early Intervention/ Parent Support.

Raising a child with a disability requires an even greater amount of information than that needed to raise a "typical" child. This information is not as easily accessed as information regarding typically developing children. Parents require this information to help promote their child's development, learn information about diagnoses and treatment options, discover national and local resources, make informed decisions and be better advocates for their child.

The author designed and implemented a resource library in the therapy area of a rehabilitation hospital, a place where caregivers of children with disabilities frequented regularly and a place where caregivers had some free time while their children received therapeutic intervention. The resource library provided a variety of information relevant to the care of a special needs child including funding, diagnoses and national and community resources.

Caregivers responded positively to the resource library. They found it convenient, helpful and filled with relevant information. Staff responded positively as well, as information was readily available to them and when indicated, they were able to suggest that parents access more detailed information in the resource library. Caregivers improved in their fund of information and confidence levels in regards to caring for their child with a disability after the implementation

phase. The resource library has continued with parents requesting that the resource library expand its features.

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Chapter One

Introduction and Background

The Setting in Which the Problem Occurs

The setting of the practicum project was the pediatric department of a rehabilitation hospital in South Florida which is owned and managed by a very large, for profit, health care corporation. At this writing, the corporation owns more than 1, 500 health care facilities, with at least one facility in each of the fifty United States. The rehabilitation hospital in which the practicum project was developed has one-hundred and eight inpatient beds and serves a large number of outpatients. The hospital serves both adults and children in several specialty departments. These are Head Injury, Spinal Cord Injury, Hand Center, General Rehabilitation, Adult Outpatient and Pediatrics. The pediatric department serves inpatient and outpatient populations. Inpatients are residents of the hospital and are more physically and/or behaviorally involved and less medically stable than the outpatient population. Outpatients live at home and come to the hospital for therapeutic services. There are eight pediatric inpatient beds of which occupancy fluctuates. The outpatient population is consistently higher than the inpatient population with an average of 5 inpatients and fifty outpatients actively on program at any given time. Patients in the pediatric department can range in age officially from 0-21, however, the clientele typically ranges from 0-15.

The pediatric department's team is staffed by rehabilitation specialists of varying disciplines. There are two full- time occupational therapists, one staff level and one

senior level, and a part-time occupational therapist who is the supervisor of pediatric occupational therapy. Staffing also includes a part-time physical therapist, who is the supervisor of physical therapy, a full-time staff physical therapist and a full-time physical therapy assistant. A full-time speech pathologist is on the pediatric team with additional speech pathology services provided by the speech pathology department personnel as indicated by the census. An outpatient and inpatient case-manager are assigned to the pediatric department. The case-managers are a social worker and a nurse respectively and both manage cases in other hospital departments as well. A psychologist who works with adults and children is assigned to pediatrics. A recreational therapist works with the inpatient population when it is indicated and at times serves outpatients. Inpatients receive respiratory therapy when indicated. A pediatric physiatrist, who works in the hospital, refers many and follows all of the inpatients and many of the outpatients in the pediatric department.

The patient population consists of a wide range of diagnoses. These include but are not limited to, Traumatic Brain Injury, Cerebral Vascular Accidents, Spinal Cord Injury, Near Drowning, Cerebral Palsy, Cancer, Burns, Spina Bifida, Autism, Sensory Integration Disorders, Learning Disorders, and Developmental Delays. Patient families are primarily English speaking but there are several whose primary language is Spanish. Caregivers of the patients are primarily the parents, both dual and single parent families. Some children are cared for by grandparents, adoptive or foster parents. Patients come from a wide range of ethnic and socioeconomic backgrounds. The inpatient population is primarily comprised of children with recently acquired injuries such as head injury or near drowning. The outpatient population consists of children who were inpatients at our facility and children with congenital, perinatal, developmental or learning problems,

without prior inpatient hospitalizations. Some children have been receiving services for years at a variety of settings while others have recently begun receiving intervention at the practicum setting.

Inpatient family members may stay with the child if they choose and many do. Most families designate a family member or relative to remain with the child. This is often someone who is not working. Some family members quit jobs to remain with the child. Others come to the hospital during the hours they are not working. Some families rarely visit the inpatient. Others are there on a consistent basis. Inpatients receive at least total of three hours of physical, occupational and speech therapies each weekday. In addition, they may receive recreational and respiratory therapies, and psychology services. When inpatients gain an appropriate attention span, they begin receiving homebound school services as tolerated. Depending on staffing and patient needs, inpatients may receive therapy on Saturday. No therapy is provided on Sunday. An inpatient stay ranges from one week to several months.

Outpatients come to the hospital one, two, three, four or five days each week. Depending on the patients' needs, they may receive one, two or three treatment sessions at each visit. These sessions may include physical, occupational and speech therapies. Each treatment session usually lasts one-half hour, thus family members who bring a child to therapy are in the hospital from one-half hour to one and a half hours at each visit. Some caregivers choose to watch or participate in treatment sessions. Some speak with other caregivers while the child receives therapy. Others utilize this time to relax or run errands as they feel their child is safe during treatment sessions. An outpatient can receive therapy from several weeks to several years.

The Student's Role in the Setting

The student's role is a full-time occupational therapist in the pediatric department. Responsibilities include evaluation and treatment of inpatients and outpatients. This includes assessing the need for, fabrication of and ordering adaptive equipment and wheelchairs as needed, communication with team members on an ongoing basis and outside medical and educational personnel as needed, participation in team and family conferences and education and training caregivers in caring for their child as it related to occupational therapy, functional activities and safety. The student is a supervisor of occupational therapy students completing internships in the pediatric department of the hospital. The student is part of a team that is responsible for educating hospital staff in how to "educate" patients. This staff education takes place at inservices to the hospital departments and as part of orientation to new clinical staff. At the time of this writing, the student is on a team to implement and train staff in use of a standardized pediatric evaluation.

Because patients come to therapy visits several times a week, therapists often become the main providers of information to caregivers. The student has been a recipient of many questions and provider of much information to caregivers including directing them to other resources. The student has seen first hand how caregiver knowledge and information yields increased control over their child's situation. This includes seeking a variety of treatment options, enrolling the child in community programs, accessing funding sources or purchasing adaptive equipment the caregiver was previously not aware existed to make their lives easier.

The student's degree of autonomy varied according to the situation. The student provided services to those children who had a doctor's prescription for therapy. Within

that provision of services, the student provided a variety of therapeutic techniques, ordered necessary equipment and provided information to caregivers. The student readily provided information that was available in the department. Resources, though, were limited and thus so was the amount of information that was provided. The student was able to suggest new program ideas to the supervisor and appropriate hospital committees.

In the areas of determining which new programs are developed, space utilization or budget, the student had little autonomy. The student did have the support of the hospital education committee. The hospital is always striving to be a leader in health care and must meet certain standards in order to be accredited by the Joint Commission on the Accreditation of Healthcare Facilities (JCAHO) and the Commission on Accreditation of Rehabilitation Facilities (CARF). Because the student's practicum helped to fulfill requirements for JCAHO and CARF, the hospital's support was given to develop a program.

The author brings credibility to her position through her experience in occupational therapy. The student has nine years experience in Pediatric Occupational Therapy and is Board Certified as a Pediatric Occupational Therapist. In addition, the student has several specialty certifications related to pediatric therapy. She has worked in a variety of settings including a University Affiliated Program, long-term care, outpatient clinic, group home, home care, school and crisis center. These experiences provided insight into the vast and varying needs of caregivers as well as the difficulties in accessing information. The author has a good rapport with colleagues and the families with whom she works and is thought to be an advocate for the families.

Chapter Two

The Problem

Problem Statement

In the practicum setting, several problems were observed in relation to caregivers having minimal necessary information. The caregivers and parents seen in the pediatric department were not well informed about many aspects of their children's disability. Parents and caregivers frequently asked many basic questions of therapists and case managers regarding their child's diagnosis, prognosis, treatment options, funding sources, exceptional educational services and their rights in relation to these services. Many questions were asked about community and statewide resources. Caregivers frequently commented that they do not have extra time in their day to seek out information, support groups or other services which may provide such information and lack the money to enroll their child in special programs in the community or to purchase books regarding diagnosis or development.

Parents were not always making well informed decisions. Parents sought out the advise of therapists, considering the therapist as expert in the child's care. On many occasions, family members looked at other patients making quicker progress than their child and asked the therapist why their child was not performing similarly. This was an indicator of a lack of knowledge about their child's diagnosis, extent of disability and prognosis. Parents required much more information than was available to them at the practicum setting.

Clinical staff were on a tight schedule. Therapists are booked back to back with patients and meetings. Accessing and providing information to families became

very time consuming for staff. The families required much more information than staff could provide within the framework of their schedule. According to Gowen, Christy and Sparling (1993) parents of children with a disability or developmental delays have a "significant" need for information especially as it relates to the child's special needs. In community and hospital services, knowledge is very important for caregivers. "Children with special needs benefit from the ability of parents and professionals to work together to develop, implement, and evaluate programs" (Shelton, Jesson and Johnson., 1989, p. 8).

Parents are not only caregivers, but are also the consumers of health care and must make decisions with professionals in a family-centered care approach which "encourages parents to exercise rights as consumers"(Shelton et al., 1989, p. 8). Joe (1997) reports that today's health care consumers must be "more cost-conscious and informed" (p. 14) in order to take on more responsibility for their health care decisions. Families needed to access information on their own to learn more about disability-related and caregiving issues. Caregivers required an easily accessible, low-cost or free place where they could access information related to their child's diagnosis and care. Staff benefit as well from easily accessible, low-cost information related to diagnoses and care.

Documentation of the Problem

The student observed that caregivers asked the staff many questions. It was also observed that staff spent much time locating and discussing information with caregivers. Both parents and staff were overheard commenting on the difficulties accessing information or the amount of time it took to locate needed and accurate information. A

literature review was completed documenting the need for and difficulties in locating information regarding caring for a child with a disability.

In order to gather facility-specific data, surveys were distributed to staff (Appendix A) and caregivers (Appendix B) to gather data regarding the problem. Staff and several caregivers were interviewed as well to assess the current method of information exchange and needs. All ten (100%) surveys distributed to staff were returned. Nineteen of thirty (57%) surveys distributed to caregivers were returned.

The response across disciplines to staff surveys were very similar. Staff found that parents ask many basic questions especially when the child first begins treatment. Parent questions addressed issues regarding diagnosis and why the child performs or cannot perform in a certain manner, treatment options including surgery, normal development, prognosis, community resources, support groups, funding sources and schooling. Some families asked unrealistic, future-oriented questions about their child. For example, a parent asked if her child with a high-level spinal cord injury would walk by her birthday which was only several months away.

According to staff, families are overwhelmed when the child has a disability. The child with the disability is not the only concern as there are often other siblings in the home, job-related and family responsibilities. Staff found that parents frequently asked the same questions and to several different staff members. Staff felt this was due to the difficulty of taking in all the information at once and needing to hear it in different ways from different people "until it makes sense". Having a child diagnosed with a disability or involved in a traumatic accident is very stressful for the family. Staff reported comments from caregivers such as "I don't know how to find information for my child"

and have asked "How do I find out information regarding (whatever their situation is)?". One therapist felt there is a "total lack of knowledge of what is going on with the child".

Staff reported a lack of decision-making and confidence on the part of caregivers. Caregivers often asked the professionals' opinions regarding care and treatment of their child. For example, parents asked therapists what school or camp the child should attend, how many days a week the child should attend or how to discipline their child. When therapists asked the caregiver for their opinion on the topic, a common caregiver response was, "you're the professional, what do you think?" Therapists were having difficulty engaging the families in determining different options and deciding on solutions for the care of their child. Professionals expressed "guilt" in making decisions for the families. One therapist expressed not wanting "the burden of making a decision for the family... that the family may not like or may not be appropriate in the end."

Staff reported that they did not have enough time in the their day to access and provide all requested and necessary information to caregivers. Staff reported feeling "overwhelmed" with the amount of work they had to complete in a day. This included patient treatment, conferences and team meetings, documentation of daily notes, evaluations and progress reports, contacting doctors and other related professionals to coordinate care for the patients and fabricating and ordering equipment for patients. Many staff members reported putting extra, unpaid time to complete work tasks and provide information to caregivers and were feeling "burnt"

The parent response to the survey found that they did not want to be thought of as a "pain" by asking too many questions. Interestingly, staff felt that caregivers did ask many questions and those who did not ask questions were deemed to be uninformed or not interested. Caregivers expressed that they did not always understand what the

therapist or case manager said, but at times were too embarrassed or too confused to ask for clarification. Some caregivers expressed that they did not know what information to ask or to be concerned with until coming across information while reading or hearing something in conversation. Overall, caregivers felt they needed a great deal of information in many areas including more knowledge about diagnoses, treatment options, community resources, school information, parenting information and information about siblings of disabled children. In addition, caregivers felt this information was not easily accessible.

According to David (1995) parents of children with disabilities respect professionals' knowledge, but do not expect them to know everything. Parents do expect professionals to be resourceful, know how to access information and guide families to resources. Parents also expect professionals to be open-minded when the parent has information to share.

The need for providing information to parents was recognized in other settings as well. In an effort to guide professionals in providing parents of children with special needs with the appropriate information, Gowen et al. (1993) developed a survey to determine the informational needs of these parents. Families of children receiving therapeutic intervention must have information. Just what information should be shared? According to Shelton et al. (1989) the answer is "everything... from medical information, to community resources, to support groups, to pros and cons of treatment choices" (p. 16). Gowen et al. found that the major informational need of parents of children with special needs is in the area of promoting the development of their children. Other informational needs were dealing with the emotional and time demands of parenting, identifying community resources, planning for their child's future and understanding their

child's legal rights. Parents must have information to better collaborate with professionals.

Therapists in other facilities recognized the need to better respond to the informational needs of families. Families wanted therapists with appropriate therapeutic and interaction skills, and effective communication skills (Lawlor and Cada, 1993). Therapists and caregivers felt that collaboration between the two groups was indicated to positively effect outcomes for the children served. Professionals and caregivers developed a guiding philosophy of working collaboratively to provide the best outcome for all parties involved, especially the children (Lawlor and Cada, 1993).

Warnat (1980) found decreased parent involvement in their children's educational programs. After parents participated in educational programs, they had increased participation and sense of responsibility in their child's educational programs. These parents also had better skills and resources to solve their problems as it related to their child's education.

Analysis of Problem

Providing information to caregivers was clearly a need. In order to develop a solution strategy to remedy this problem and provide the required information, it was necessary to analyze the contributing factors to the problem. Some of these factors are interrelated. These factors are:

Lack of staff time
Managed Care constraints
Department structure
Caregivers' need for information
Difficulty accessing information
Lack of caregiver time and funds
Lack of hospital funds

Lack of organization of resources

Lack of staff time. One factor which contributes to the problem is a lack of time in the practicum setting to access and provide information. Although caregiver education is an important part of therapy, this often caused therapists to use more than their allotted time slot for therapy, causing them to be late for their next patient or meetings. Providing information to one family took time away from another family. Family members had questions that staff could not adequately or completely answer due to time constraints or lack of available, easily accessible, appropriate resources. Some staff took time out of the child's treatment session to speak with and educate caregivers, but felt as though they were cheating the child of needed "hands-on intervention". Staff are required to complete paperwork in the course of their daily schedule. It is difficult to complete all work-related obligations and access and provide information needed by caregivers in the course of a day. Although some staff reported staying late, coming in early and working through lunch in an attempt to complete all tasks, there was still "never enough time".

Case managers expressed concern of not getting their job done efficiently and timely as they were talking to families or making calls for the caregivers - calls the caregiver can make independently if provided with the appropriate resources and information of whom to call. Case managers felt their case load was very large and they are unable to provide "the best service" to families. Caregivers have many questions and concerns and it is "impossible" to spend time investigating all questions. There is too much "busy work" to be completed in addition to all their other obligations, including getting services funded.

Managed Care constraints. Lack of time to complete all necessary tasks in the health care setting is common. A current challenge to the health care system is reduced

health care funding (Costello, Bracht, Van Camp and Carman, 1996). Health care has become a business, with health care companies dedicating more time to generating profits than to improving the quality of care (Ireys, Grason and Guyer, 1996). Therapists are under increasing amounts of pressure to see more patients in a day, and increase productivity in order to generate more billing for the hospital. Time is not allotted in the schedule for "family education" unless this is done during billable therapy time. Therapists must be accountable to their employer as to how their time is spent. Managed care has become a common funder of services. Managed care organizations (MCO's) often includes one or more of the following:

> Prior, concurrent, and retrospective review of the medical necessity and appropriateness of services or sites of services; contracts with selected health care providers; financial incentives or disincentives related to the use of specific providers, services or service sites; controlled access to and coordination of services by a case manager; and payor efforts to identify treatment alternatives and modify benefit restrictions for high-cost patient care. (Platt, 1993, p. 350)

MCO's frequently limit the amount of reimbursed therapy sessions. Evaluations are often reviewed prior to the onset of therapeutic intervention. This delays the time that intervention commences. Sometimes, therapy is not approved for the child. In this circumstance, caregivers only have one evaluation visit in which all their questions can be answered- a difficult task. If therapy is approved by the MCO, often it is a limited number of visits. An example seen in the practicum setting was approval of six weeks of therapy for a child diagnosed with Cerebral Palsy. Cerebral Palsy, in addition to many developmental or traumatic-onset disabilities, requires extended amounts of intervention.

A pediatric physical therapist ponders:

> Imagine trying to teach a family everything they need to know about managing the physical complications that result from Cerebral Palsy throughout a child's life in just six weeks! These kinds of (MCO) limits don't even begin to take into account the changing needs of a child as he grows and develops both physically and cognitively (Woods, 1996, p. 39).

Parents expressed some negative ways in which information was delivered. Information was given to them in terms they did not understand, too little information was provided, unnecessary information was provided, and information was often provided in a "one-shot" procedure (Moffitt, Reiss and Nackashi, 1992).

Department structure. A third contributing factor is the structure of the department around the child's needs. Although all staff were aware of the importance of family education, the structure of the department is focused on providing rehabilitation services and therapy to the child. Often a family's needs came secondary to the child's therapeutic needs. Bazyk (1989) found that basic professional preparation and philosophy is hands-on, child-centered services. Indirect service, consultation and promoting partnerships between therapists, other professionals and families in professional preparation and in the clinic setting receive less attention and implementation (Lawlor and Henderson, 1989).

There are those who believe that the professional is the expert and can make decisions for a child independent of the family. This only fosters dependence of family on professionals (Shelton et al., 1989; Dunst, Trivette and Deal, 1988). Professionals may feel they have the expertise based on their schooling (Lawlor and Cada, 1993) but partnerships between parents and professionals must be fostered in order to empower

families to assist in solving problems and become better advocates for themselves and their children. (Dunst et al.).

Caregivers' need for information. A fourth factor contributing to the problem is the great amount of information the caregivers need (Santelli, Turnbull, Sergeant, Lerner and Marquis, 1996). Parents in the practicum setting asked frequent and similar questions. According to Shelton et al. (1989) "information, particularly disturbing information, is difficult for anyone to absorb fully" (p. 17). The newness and unfamiliarity with the hospital and therapeutic environment generates many questions. Moffitt et al. (1992) found that "families express an overwhelming sense of frustration in trying to get information as it applied specifically to their child and their child's illness" (p. vi). Families are in constant search for new and different information and every stage in life brings new challenges with new information needs. Janinski (1994), the mother of a child with special needs, reports there is a "constant search for new treatments and therapies" (p. 41).

Difficulty accessing information. The fifth factor contributing to the problem is the difficulty in accessing disability-related information. Raising a child with a disability is different than raising a typically developing child. Caregiving demands are usually greater when the child has a disability (Beckman, 1983). The issues are different, it is more time-consuming and information is not as easily accessible. According to Gowen et al. (1993) friends and family of parents of children with special needs cannot provide sufficient and appropriate information as a typical child's needs are different from those of a special needs child. Parents often ask information of coworkers, but it is not likely that a caregiver's coworker has a child with a disability. Thus, this avenue of accessing child-rearing information is not useful. Janinski (1994) reported that her "other friends

cannot understand" (p. 41) the child-rearing issues specific to her son's disability.

Lack of caregiver time and funds. A sixth contributing factor was that parents often do not have the time to access needed information or the extra funds to purchase informational materials. Having a child with a disability or a chronic illness consumes much of the parents' time ("Parenting a Child with Special Needs," 1993). Frequent evaluations, appointments with specialists, therapy visits, and special schooling are common. These services often require time and money. Children with disabilities commonly require special medications, machinery (i.e. heart monitors) and surgeries, requiring demands on the family's time and finances. If a parent works, work schedules must be juggled to accommodate the child's schedule. Other children in the family require time as well and their schedules must be juggled to accommodate the child with special needs.

Lack of hospital funds. The seventh contributing factor to this problem is a lack of sufficient funds to purchase educational materials. A budget was set aside for staff resources, however purchasing resources geared specifically for families and caregivers was not established. Although caregivers were given some information by professionals, caregivers did not have access to therapists' books. Caregivers were given information the staff thought they should have or needed based on conversations between them. Staff may have misunderstood caregivers concerns and thus provided the family with irrelevant information. Because information came from professional texts, much information was provided with technical jargon that families did not understand.

Lack of organization of resources. Some educational materials, recent and outdated, did exist in various departments within the hospital. Because space, staff and time to organize and maintain these resources were not allocated, these resources were not

organized in an accessible place or convenient manner. One department was not aware of another department's resources and some staff were not familiar with their own department's resources. This frequently happens in health care facilities. The day to day health provision of patients is attended to and the educational needs of patients are not as manifest (International Federation of Library Associations and Institutions, 1984). In view of shrinking funding for health care, private and public, families must be provided with a great deal of information and options and incorporated into decision-making.

In light of this analysis, it was apparent that families required access to and should be provided with clear, understandable information in order to be partners with professionals in their child's care and to make informed decisions. In addition, staff required easily accessible information to decrease the time involved in accessing and providing information. This information needed be in close proximity to the pediatric unit where the pediatric patients received intervention. Information should be free and easily accessible so that parents can use these resources while their child is in the hospital or receiving therapy. Families would not have to schedule a trip to the library or purchase resources. They can access information in a relaxed manner knowing their child is occupied and in trusted hands.

In addition, the hospital budget needed to be revised to include the provision of educational materials relevant to caregivers. Included in this budget should be resource materials and staff to organize and maintain these materials. Space also needed to be allocated to house these resources in an organized fashion.

Chapter Three

Goals and Objectives

In the problem analysis, it was established that the caregivers of children with special needs frequently require a great deal of information in order to become better educated in their child's care and partners with professionals. The lack of information led to a small fund of knowledge, decreased confidence and lack of informed decision making. It had also been established that staff did not have adequate time or available resources to provide the caregivers with the needed information.

Goal:

To increase caregivers fund of information and enhance levels of confidence in regards to caring for their child with special needs.

Objectives:

1. By the fourth week of the practicum, caregivers will have access to at least fifteen different diagnosis-related books and/or parenting books, fifteen diagnosis-specific pamphlets, a list of local and national disability-related organizations, and a list of community resources. (List of resources to be included in practicum report.)

2. By the end of the ten-week practicum, caregivers will increase the amount of information they have about their children's diagnosis as indicated by an average increase of one point on a pre/post test analysis of group data when questions 16, 17 and 18 are averaged and Information Assessment 1 (IA 1) is compared to Information Assessment 2 (IA 2).

3. By the end of the ten-week practicum, caregivers will increase in knowledge of

community resources as indicated by an average increase in knowledge of community resources as indicated by an average increase in response on group data of three new community resources listed in question 20 when IA 1 is compared to IA 2.

4. By the end of the ten-week practicum, caregivers will increase in their information level of developmentally appropriate tasks for their children as indicated by an average increase of one point on a pre/post analysis of group data of question 22 when IA 1 is compared to IA 2.

5. Caregivers will be able to identify three new developmental activities they have implemented with their children (question 23A).

6. By the end of the ten-week practicum, caregivers will increase in feelings of comfort in dealing with and speaking to professionals as indicated by an average increase of one point on a pre/post analysis of group data when questions 24, 25, 26, and 27 are averaged and IA 1 is compared to IA 2.

7. By the end of the ten-week practicum, caregivers will increase in their confidence in advocating for their children as indicated by an average increase of one point on a pre/post analysis of group data when questions 28, 29, 30, and 31 are averaged and IA 1 is compared to IA 2.

8. By the end of the ten week practicum, caregivers will increase in their awareness of how to access information about their child's care as indicated by an average increase of one point on a pre/post analysis of group data when questions 33 and 34 are averaged and IA 1 is compared to IA 2.

Chapter Four

Solution Strategy

Review of Existing Programs, Models and Approaches

The literature frequently cites the need for providing information to caregivers and a variety of ways to provide information to caregivers have been developed. Providing information to caregivers and involving them in the care of family members helps them regain some control of a situation whereas help-giving leads to feelings of loss of control (Joe, 1997; Dunst et al., 1988). This is especially true when a family member is in the hospital or is receiving therapeutic intervention on an outpatient basis. In the past, hospital stays were longer than they are today. "With the trend toward shorter hospital stays, education programs need to include patient teaching as an integral component" (Nowicki, 1996, p. 264). This will help families be part of the therapeutic team and maintain some control.

When in a hospital or therapeutic situation, the patient, client and/or caregivers are in obvious need of some professional assistance. The hospital setting is also one in which some control is taken from the patient and caregiver. The staff and professionals decide when therapy is provided, when meals are served, when visiting hours begin and end, and even when showering occurs. This lack of control can decrease patients' and caregivers' self-confidence and self-esteem. Although the patients are in need of help, help-giving may produce some negative effects. When families are given much help in an atmosphere where the professionals are perceived to have all the expertise, it can lead to families learning helplessness, becoming dependent on professionals and decreasing

self-esteem (Dunst et al., 1988). When families are provided with appropriate information and assist in decision-making, they are able to regain some control.

Providing information to families and caregivers is not a new idea. In an effort to improve the quality of care with a small budget and staff at Community Coordinated Child Care of Louisville and Jefferson County, a learning resource center was opened (Heberle, 1977). This learning resource center, open to the public, was geared toward typically developing children. Through accessing information at the learning resource center, caregivers reported increased feelings of competence in parenting abilities.

Providing information to caregivers is not isolated to this country. In Israel, an educational program including home visits to new mothers of typically developing children by nurses and paraprofessionals yielded significant results. Mothers were provided with information on development, temperament and the physical needs of the infant. After the study, these mothers showed more positive parent-child interactions, improved physical care of the child and increased outcomes for the mothers, such as seeking additional education or becoming employed (Parush and Hahn-Markowitz, 1997).

The Parent-Child Program at the Center for Development, Education and Nutrition in Austin, Texas (Goetz,1992) provides education to caregivers about child development in the home setting. Providing education in the home is an appropriate way of assessing family situations and needs, but families are often taught the chosen curriculum of the program. Caregivers cannot freely peruse information in an effort to determine what it is they want or need to know.

Therapists and families at the University of Illinois at Chicago Therapeutic Partnership Project developed a guiding philosophy for collaboration. This included

"forming effective partnerships with young children, their families and other providers, and using the caregivers' knowledge to maximize developmental outcomes" (Lawlor and Cada, 1993, p. 28). The belief is that collaboration will result in favorable outcomes for children. Although a guiding philosophy is a good beginning, more concrete procedures on how to form "effective partnerships" would be more appropriate.

The Family Resource Center on Webster Avenue in Rochester, New York, and Family Tree Parenting Center & Counseling Service in Lafayette, Louisiana (Goetz, 1992) host parent education courses and seminars in specific topics related to child development and parenting. Classes on development are imperative, but cannot accommodate the variety of work and family schedules to which caregivers must adhere.

At Virginia's Family Focus, infant and toddler play groups were developed. These groups met twice weekly and provided a format for educating parents (Family Resource Centers, 1990). These groups found that by providing information on child development and tools for responding appropriately to children in an informal group format, primary prevention and treatment of child abuse, neglect and developmental delays was accomplished. This group format is an ideal way to relay information to caregivers in a non-threatening manner and to provide peer support.

A resource library has been established at The Parenting Center at Children's Hospital in New Orleans, Louisiana (Goetz, 1992). The resource library, established about sixteen years ago, was developed in response to requests from parents who attended parenting classes at the Center. They wanted more information about parenting and development. The resource library has books, videos, magazines and some pamphlets on many topics related to child development, pregnancy, parenting and family issues. The Parenting Center has a budget of $3, 000.00 to $4, 000.00 annually. Membership at the center is

required to check out books. Depending on the level of membership, the fee is $25.00 or $50.00 annually, although scholarships are available for those in need. Books may be checked out for two weeks and videos for ten days. A receptionist sits at the front desk of the library to check out books. A staff member oversees the library and ordering additional materials (D. Newton, Director of The Parenting Center, personal communication, June 5, 1997).

The information in the resource library helps to motivate parents and reinforces what is discussed in the parenting classes. One parent often brings home information to their partner so they can both have similar information. The resource library is an easy way to access information. The information helps to dispel myths parents have heard about child rearing and helps parents feel more competent in their roles (D. Newton, personal communication, June 5, 1997).

Parents Place in San Francisco, California has established a Parenting Library (Goetz, 1992). The Parenting Library was established in the early 1980's to empower the parents through education and to provide socialization for the parents. The library houses books, videos, magazines and a binder of articles on topics such as parenting, child care, health care, pregnancy, birth and family entertainment. The library is open when the Parents Place is open. There is no "permanent staff" in the library. Library membership is $15.00 per year. If a patron would like to check out a book, he or she finds the administrative assistant of Parents Place. This reportedly is easy as the building is small. Information from the binder can be photocopied on request. Parents Place recently computerized their library and discovered there has been a fair amount of loss of materials. The use of the computer to track materials is intended to decrease loss (M. Lopez, personal communication, June 2, 1997).

Pilot Parent Partnerships (PPP) in Phoenix, Arizona (Goetz, 1992) has a lending library of books and videos. The resource coordinator at PPP reports that the lending library was established to offer an option to families to have additional or in-depth information. The lending library has information related to disabilities and issues that arise when raising a child with a disability. Some of these are accessing the educational system, sexuality, recreation, play and entering adulthood. The library is open when PPP is open, but they have few walk-ins. Because PPP serves the state of Arizona, items are frequently requested over the phone and are then mailed to the family. Any resident in the state is eligible to use PPP's lending library. When a family contacts PPP, they receive a packet of information including a bibliography of contents in the lending library. Items added to the lending library are announced in their newsletter. PPP finds that providing access to current information to families is helpful. "It lets the family know their options and families do not feel so alone" (K. Pastores, personal communication, June 2, 1997).

The Middle Country Public Library in Centereach, New York (Goetz, 1992; Cohen and Simkin, 1994) has established a resource center with audio and videotapes, books, periodicals and pamphlets for families, caregivers and professionals working with families. The resource center was developed with funding from the New York State Developmental Disabilities Planning Council to provide information to parents and professionals on parenting and disability issues (Cohen and Simkin). Information that connects patrons to resources and organizations that offer additional information and assistance on specific issues is provided as well. The subjects included in this collection are general parenting, child development and special needs (B. Jordan, Librarian, Middle Country Public Library, personal communication, May 2, 1997). In addition to the

materials in the resource center, staff attitude towards the target population is very important (Cohen and Simkin).

These attitudes correlate closely to the family support principles. The guiding principles reflect a reliance on partnerships with parents (Feinberg and Feldman, 1996; Cohen and Simkin, 1994).

- The relationship between the resource center and family is one of equality and respect.
- The program facilitates parents' ability to serve as a resource to each other, to participate in program decision and governance and to advocate for themselves in the community.
- The program is community-based and culturally and socially relevant to the families they serve.
- Parent education, information about human development, and skill building for parents are essential elements of the program.
- The program is voluntary and seeking support and information is viewed as a sign of family strength, not as indicative of deficits and problems. (p. 145)

Two programs existed in the vicinity of the practicum setting. Florida Diagnostic and Learning Resources System (FDLRS) was established in response to public laws mandating informational needs to parents of special children. Public Law 99-457, the 1986 amendments to the Education of all Handicapped Children Act of 1975, recognized the role of parents as the primary decision-makers regarding the care and education of their children. In addition to providing parents with information, educators were in need of informational and educational material in order to appropriately include children with special needs into their classrooms (C. Genovese-Shulman, FDLRS Media Center Coordinator, personal communication, April 10, 1997).

FDLRS has nine locations throughout the state of Florida. In the local area, FDLRS is housed within the county's Main Library. It contains books, videos, test kits and

informational material related to a large variety of disabilities and exceptionalities and parenting. Anybody can use the library material in the library. A FDLRS library card is needed in order to check out materials. A person having a county library card is eligible for a FDLRS library card. FDLRS is staffed by several librarians who maintain and update the library as needed. Material purchases are decided by a committee from the county school board and library. A librarian is available to help patrons access resources and is able to provide a great deal of information about programs and contacts in the community.

FDLRS is an excellent community resource, but some caregivers from the practicum setting reported that they do not have time to go to FDLRS and access their resources. Caregivers time was spent at their place of employment, transporting their children to and from school and special activities, taking the child with a special need to therapy and medical appointments and in general caregiving tasks. The caregivers also expressed that they did not have adequate child care, so that they may use FDLRS without distraction. Caregivers of inpatients often worked during the day and did not want to miss spending time with the patient to visit an off-site library.

Family Central, another local establishment, has a resource library. The resource library was established in response to needs identified by Family Central's staff. When staffing and organizing community child care centers, Family Central staff members recognized that there was little educational materials in the child care center and little funding to purchase these materials. A main resource center would allow the child care center staff to borrow materials as needed to provide developmentally appropriate activities in the classrooms (L. Waters, Early Childhood Resource Specialist, personal communication, May 22, 1997).

The Family Central Resource Library has expanded and is now open to the public. Housed in the resource center are parenting resources, children's books, toys and games, records, audio and video tapes and parent and teacher magazines. Family Central is geared toward typically-developing children and has little disability-related information. The resource library includes a story time and craft activities for children. The resource library is free to anyone living in the county and to child-care workers in the county. Others who wish to use the resource library pay a $20.00 annual fee. The resource library is staffed by a resource specialist who is available to guide patrons to appropriate materials, answer questions and guide patrons to other community resources. New purchases are obtained as indicated by staff and patrons requests.

The resource library has grown to include a variety of patrons. Early childhood educators and community individuals from high and low socioeconomic backgrounds access the library. Because there are several retirement communities in the area, seniors who have grandchildren visiting for several weeks a year use the library to borrow appropriate materials. This is a great service for the seniors on a tight budget whose grandchildren's needs change annually (L. Waters, personal communication, May 22, 1997). Family Central's Resource Library is another great resource, but it has little disability related information and again the caregivers in the practicum setting have extremely busy schedules and often cannot find the time to access this resource.

Solution Strategy

After reviewing and examining the existing programs, models and approaches, some were not chosen as they did not fit with the practicum setting and would not accomplish

dissemination of information to caregivers. Establishing and maintaining a guiding philosophy was deemed to be too passive and would not provide information to caregivers. Home visits were not feasible as the practicum setting is not licensed as a home care agency. Parent education classes were not an option as conducting these classes was not cost-effective. Developing an infant/ toddler play-groups was difficult as similarly developing children needed to be grouped. This required changing many of the patients' and therapists' schedules for the time-frame of the practicum and was not well received by hospital personnel.

The solution strategy involved the development of a resource library in the pediatric department of the hospital. Hospital libraries have many benefits. They can save lives (Quinn and Rogers, 1991) by providing professionals with information allowing them to handle some aspect of patient care differently. They provide information to patients and families to help them collaborate with professionals in their care. Providing education to patients and caregivers enables them to be involved in their own care (JCAHO, 1996; Koepke, 1994). Shelton et al. (1989) found "parent/professional collaboration can lead to more comprehensive and appropriate care plans that are individually tailored to both the child's and family's strengths and needs" (p. 7).

In a resource library, caregivers can access information that can prevent child abuse and neglect. Lack of knowledge and lack of problem-solving skills are some factors that lead to child abuse. Child abuse and neglect can be decreased by providing caregivers information on child development, child-rearing attitudes, parent-child interaction patterns and parental skills and competencies (Family Resource Centers, 1990; Breckbill and Carmen, 1994). "Visual, auditory, language, sociological and psychological dysfunctions are some conditions that put children at risk" (Gold, 1988, p. 134) for child

abuse. The children receiving therapeutic intervention at the practicum setting have the above conditions in addition to physical handicaps. By discussing issues with library staff and providing caregivers with information on development, caregivers may realize that the behavior their child is displaying is expected and typical. With information, the caregiver can develop new strategies to deal with the problems the child or the caregiver is experiencing (Family Resource Centers).

The State of Florida has recognized that the risk of child abuse can be reduced by providing parents with adequate resources (Levine, 1997). These resources are early health care, parent outreach and family support. Part of parent outreach and family support is providing parents and caregivers with appropriate information about parenting, development and linking families to community resources. Because budget cuts are becoming more prevalent, staffing at libraries continues to be decreased. This is another reason to provide even more information to caregivers in written, audio and video formats (Gold, 1988).

All parents need practical information on child development and behavior. This is especially true in the early years, the time of major impact on a child's development and when parents are forming their approaches to child-rearing (Rothenberg, 1983). According to Wagonseller (1992), there is lack of formal training for parents yet parents have the responsibility of teaching their children to develop skills and values to survive in society. Providing parents with information has helped parents develop confidence in their parenting abilities and "become more comfortable with their child's individual development and personality" (Rothenberg, p. 7)

Parents of children with special needs require an even greater amount of information (Santelli et al., 1996). According to a parent of a special needs child in Shelton et al.

(1989) "The more you know, the less scary the future looks" (p. 16). This information is not as easily accessed as information regarding typically developing children. Information on special needs can be technical. Information provided to families should be in laymen's terms and linked with the appropriate medical terminology (Shelton et al.). There is ongoing need for information and services (Parenting a child with special needs, 1993; Santelli et al.). The information needs of these parents change as their child's needs change and as their children reach transition points. Although children with special needs may receive special education and therapies, these only last a set number of hours each week. Parents have a unique opportunity to teach their children a variety of everyday tasks and concepts in the home (Honig, 1978). In order to become effective as parents and teachers, parents of children with special needs require sufficient and appropriate information and access to resources.

Hospital libraries can be a "powerful mechanism for facilitating the sharing of information" (Shelton et al., 1989, p. 18). According to Bergen, a physical therapist, "Information is power... providing information is leveling the playing field" (Segedy, 1997, p. 39). As therapists, we provide essential services to infants and young children and their families (Dunn, Campbell, Oetter, Hall and Berger, 1989). However, providing the families with all information is not a reality. New questions can develop daily. Providing all information does not assist in developing caregiver ability to access this information independently. Families receive services at our facility for a limited time. We do not empower caregivers by spoon-feeding them information. Oster in Shelton et al. (1989) found that "Information can also bring a sense of power and control to a family who may feel more hostage than partner to a gang of powerful professionals" (p. 27).

Sharing information helps parents become more independent. When a parent is taught

to be independent over their child's situation it can increase the competence of parents (Shelton et al., 1989). A parent quoted in Shelton et al. was happy her child's trainer would "teach us how to teach her so that if we ever found ourselves without services we would still know how to facilitate progress" (p. 16). In addition, staff can filter information given to families. If parents are to truly be partners in their child's care, they should be given access to as much information as possible in order to advocate appropriately for their child. Information should be given in manageable doses (Shelton et al.) and at the caregivers pace. A resource library would allow caregivers to access the information they need at their own pace and caregivers can then bring their questions to professionals if they choose.

Shelton et al. (1989) found that "meaningful, parent/professional collaboration at all levels is the driving force to ensure quality health care for children and their families" (p. 7). Wagonseller (1992) found that when parents and professionals work as partners, children's academic skills increase and behavior-type problems decrease. In response, early childhood disciplines are developing partnerships with family members (Lawlor and Cada, 1993).

According to Honig (1978), serving parents of children with special needs by involving them in the care and programs of their children will better serve the children. Providing information to caregivers can help involve parents in their child's care. Although "offering parent information is not a panacea...such a program can introduce parents to new perspectives for raising their children" (Downs and Walker, 1996, p. 32).

In order to develop a pediatric resource library at the practicum setting, top-level support of hospital personnel had to be secured. The education committee of the hospital needed to approve the student's ideas in order for them to be implemented. A

proposal with the solution strategy was presented to the education committee. As new information was learned, it was shared with the education committee chairperson who then passed this on to the education committee members.

The solution strategy included securing a small room off the pediatric gym area to be used as the pediatric resource library. The room was to contain a bookshelf and vertical file to house resources. Also included was a desk, two tables and several chairs. The library would be open Monday and Thursday afternoons, Wednesday, Thursday and Sunday mornings, and Tuesday evenings. These times accommodated the outpatient and inpatient schedules. A rehabilitation technician was requested thirteen hours a week to staff the library and assist patrons with accessing information and to help organize and maintain materials.

Current hospital resources were gathered (Appendix C). Additional, current disability-related resources and a subscription to Exceptional Parent magazine were ordered. National disability-related organizations were contacted to send printed information and disability-related product catalogues were obtained from a variety of vendors. A box into which caregivers can drop requests for materials to be photocopied as permitted by copyright was available. The student and rehabilitation technician had access to a copy machine to photocopy the information requested by patrons. Patrons signed with initials in a notebook when using the library to track frequency of resource library use.

A computer with medical databases and internet access was proposed to be placed in the resource library to maintain current information, allow caregivers to access the information they need and to link caregivers with a support network. This, however, was not implemented. The hospital did not have a computer for staff or patients. The internet

is able to provide an enormous amount of information. Once the computer with appropriate software is purchased and a phone line dedicated to its use, internet access is free through the local public library system, SEFLIN (New Horizons, 1997). According to Cohen and Simkin (1994), parent resource centers should have computer capabilities and should consider subscribing to appropriate databases such as MedLine and ERIC.

The literature documents the benefit of internet access and online services for parents of children with disabilities. These services sometimes are the first contacts with other families in a similar situation (Schive, 1994). Schive also found that technology (internet) has made life easier for those with newly diagnosed infants. Information is gained and parenting skills improved through internet access. According to Castanoli (1994), a parent with a child with special needs who has learned a great deal from the internet:

> I have learned that my child is not a freak. I know (my son) has a medical condition that is treatable through medication and behavior modification techniques, many of which I have learned about through e-mail exchanges with other parents on the list. I have learned how to be a better father to my son. I have also learned about the challenges that lie ahead. I know about the potential pitfalls of elementary school and higher education and I am ready to deal with problems as they arise (p. 39).

Schive spoke with several parents of children with special needs who all recommend the internet to anyone for the information that is available.

Some factors that facilitated implementation of the pediatric resource library were the new Joint Commission on Accreditation of Healthcare Organizations (JCAHO) standards on education which needed to be met and the hospital's desire to be accredited by the Commission on Accreditation of Rehabilitation Facilities (CARF). The JCAHO standards (1996) which could be met with the development of a resource library were:

PF. 1.6 Patients are educated about rehabilitation techniques to help them adapt or function more independently in their environment.

PF. 1.7 Patients are informed about access to additional resources in the community.

PF. 1.8 Patients are informed about when and how to obtain and further treatment the patient might need. (p. PF 3)

Because some patients cannot understand educational material and do not make decisions independent of their caregivers, patient is included to mean caregiver when indicated.

In order to measure changes in caregiver fund of information and confidence levels as a result of using the resource library, pre and post tests were used. Information Assessment 1 (Appendix E) was given to caregivers prior to using the resource library. The second questionnaire, Information Assessment 2 (Appendix G), was given at the end of the ten week practicum period. In addition, the Library Use Survey (Appendix F) was completed by resource library patrons at each library visit in order to obtain immediate feedback from all library patrons.

Some factors impeded the development of the pediatric resource library. These were lack of space and the costs involved in starting and maintaining the resource library. Because new programs are always developing in the hospital and departments are changing in size, adequate space is a consistent problem in the hospital. Departments are frequently moved from one space to another and/or departments are combined into one office. The hospital is undergoing construction to accommodate new programs and is currently seeking approval from the city to purchase land adjacent to the hospital to expand the facility.

The start up cost of a pediatric resource library was expected to be another impeding

factor. The hospital does not have a budget created for patient education materials. Designating a staff member thirteen hours a week also posed a problem. The pediatric resource library was designed to be a free service. The student needed to convince the education committee through memos and presentations that the pediatric resource library would be an asset to the hospital and a benefit to patients, caregivers and staff.

In order to convince the education committee, the student met with the committee twice and sent several memos to the committee members. Establishing a pediatric resource library was well-received, but providing a room and designating a staff member thirteen hours a week to the library was not. Designating a staff member three to five hours a week to assist with organizing and maintaining the library and photocopying materials was approved along with a budget of $500.00. Because a pediatric resource library was more a "department issue" than a "hospital issue", the student met with the clinical director to discuss the remaining details.

The student and clinical director decided on space for the pediatric resource library. This was a small area in a room also used as the quiet room and school room. A schedule was made to determine the hours it can be used for the resource library. An empty bookshelf and vertical file were available in the hospital to house resources. When this proposal was approved, the clinical director allowed use of hospital office supplies such as hanging folders, manila file folders, binders and the copy machine as needed.

During the documentation of the problem phase, specific data was gathered on the information needs of caregivers from the staff and caregiver perspective. Pediatric staff completed a Staff Questionnaire on Parent Information (Appendix A) and caregivers completed the Resource Assessment (Appendix B). The responses to these questionnaires provided concrete evidence that caregivers required a great deal of

information, but did not have many mechanisms to access information.

The Library Use Survey (Appendix F), Information Assessments 1 (Appendix E), Information Assessment 2 (Appendix G) and the cover letter (Appendix D) for the Information Assessments was approved as was the use of a sign in book to determine how often the resource library was used. Once approval was granted, the student was able to develop the proposal.

Objective 1. By the fourth week of the practicum, caregivers will have access to at least fifteen different diagnosis-related books and/or parenting books, fifteen diagnosis-related pamphlets, a list of local and national disability-related organizations, and a list of community resources. List of resources to be included in practicum report.

In order to meet the first objective of providing the caregivers with diagnosis-specific, parenting, organizational and community information, it was necessary to determine the caregivers' specific information needs. This was determined with the Resource Assessment (Appendix B). Based on the responses to the resource assessment, books were purchased. The student was able to utilize an intern in the pediatric department to assist in gathering and organizing resources.

The pediatric intern and the student shared a phone list of national disability-related organizations and called to request information. The student called several specialty equipment suppliers and requested catalogues to be sent to the hospital. The information and catalogues were provided free-of-charge. When all the resources were gathered, they were sorted and catalogued to make them easily accessible to the patrons.

Objective 2. By the end of the ten-week practicum, caregivers will increase the amount of information they have about their children's diagnoses as indicated by and average increase of one point on a pre/post analysis of group data when questions 16, 17

and 18 are averaged and Information Assessment 1 (IA1) is compared to Information Assessment 2 (IA 2).

By providing the information gathered to meet objective 1, it was expected that the second objective of would be met. Based on literature review, interviews with colleagues and professionals in the field, it was expected that by providing caregivers with a variety of information related to parenting, disabilities, health care, development, and community and national resources, the caregivers would increase in their knowledge of diagnoses. In order to establish a baseline of caregivers' fund of knowledge and confidence level, a questionnaire, Information Assessment 1 (Appendix E) was distributed to caregivers prior to using the resource library. A cover letter (Appendix D) attached to Information Assessment 1 explained the resource library project to the caregivers. A similar questionnaire with some additional data requested, Information Assessment 2, (Appendix G) was distributed at the end of the practicum period in order to measure the changes. Changes in amount of information caregivers have about their children's diagnoses were measured by averaging all the responses to questions 16, 17 and 18 on IA1 and comparing them to the average of all the responses to questions 16, 17 and 18 on IA 2.

Objective 3. By the end of the ten-week practicum, caregivers will increase in knowledge of community resources as indicated by an average increase in response on group data of three new community resources listed in question 20 when IA 1 is compared to IA 2.

Changes in the knowledge of community resources were measured by compiling the community resources listed by caregivers on question 20 in IA 1. These community resources were compiled from question 20 when IA 2 was completed by caregivers. It

was expected that three new community resources will be added to the list compiled from IA 2 as compared to IA 1.

Objective 4. By the end of the ten week practicum, caregivers will increase in their information level of developmentally appropriate tasks for their children as indicated by an average increase of one point on a pre/post analysis of group data of question 22 when IA 1 is compared to IA 2.

Based on literature review, interviews with colleagues and professionals in the field, it was expected that by providing caregivers with a variety of information related to parenting, disabilities and development, the caregivers would increase in their knowledge of developmentally appropriate tasks. Changes in amount of information caregivers have about developmentally appropriate tasks were measured by averaging all the responses to question 22 on IA1 and comparing them to the average of all the responses to question 22 on IA 2.

Objective 5. Caregivers will be able to identify three new developmental activities they have implemented with their children (question 23A).

Caregivers responses to question 23A on IA 2 were compiled. It was expected that caregivers would be able to identify three new activities they have implemented with their child based on using the resources in the library.

Objective 6. By the end of the ten-week practicum, caregivers will increase in feelings of comfort in dealing with and speaking to professionals as indicated by an average increase of one point on a pre/post analysis of group data when questions 24, 25, 26, and 27 are averaged and IA 1 is compared to IA 2.

Based on literature review, interviews with colleagues and professionals in the field, it was expected that by providing caregivers with a variety of information related to

parenting, disabilities, diagnoses and development, the caregivers would increase in their comfort level in dealing with professionals involved in their children's care. Changes in comfort level were measured by averaging all the responses to questions 24, 25, 26, and 27 on IA1 and comparing them to the average of all the responses to questions 24, 25, 26, and 27 on IA 2.

Objective 7. By the end of the ten-week practicum, caregivers will increase in their confidence in advocating for their children as indicated by an average increase of one point on a pre/post analysis of group data when questions 28, 29, 30, and 31 are averaged and IA 1 is compared to IA 2.

Based on literature review, interviews with colleagues and professionals in the field, it was expected that by providing caregivers with a variety of information related to parenting, disabilities, diagnoses, development, community and national resources, the caregivers would increase in their confidence in advocating for their children. Changes in confidence level were measured by averaging all the responses to questions 28, 29, 30, and 31 on IA1 and comparing them to the average of all the responses to questions 28, 29, 30, and 31 on IA 2.

Objective 8. By the end of the ten-week practicum, caregivers will increase in their awareness of how to access information about their children's care as indicated by an average increase of one point on a pre/post analysis of group data when questions 33 and 34 are averaged and IA 1 is compared to IA 2.

Based on literature review, interviews with colleagues and professionals in the field, it was expected that by providing caregivers with a variety of information related to parenting, disabilities, diagnoses, development, community and national resources, the caregivers would increase in awareness of how to access information about their child's

care. Changes in awareness were measured by averaging all the responses to questions 33 and 34 on IA1 and comparing them to the average of all the responses to questions 33 and 34 on IA 2.

Because approval for the pediatric resource library was granted prior to development of the proposal, it was hoped that many of the obstacles would be worked through prior to implementation. One anticipated problem, though, was the budget limitation. The budget of $500.00 to purchase new materials was inadequate to meet the needs of the caregivers in the practicum setting. In order to provide for this limitation, the student continued to access free information from a variety of organizations. Caregivers were referred to a local library such as FDLRS which has a great deal of disability-related information. Caregivers were also referred to and have access to a myriad of phone numbers and addresses for local and national organizations.

Another potential obstacle was loss of materials from the resource library. Although there was no option to checkout books and caregivers were be able to request photocopies of information, decreasing the need to take information, a certain amount of loss was expected. To provide for this obstacle, the student maintained a master copy of those items which can be photocopied. The library was monitored daily and missing resources were be photocopied and replaced as needed.

If a lack of use of the resource library was noted, the student encouraged staff to increase talking to caregivers about the library and the student increased the amount of flyers in the hospital and distributed to caregivers.

In order to address unanticipated obstacles, the student maintained a log in which anecdotal information was recorded on a weekly basis. Problems were brought to the attention of the student. The student and pediatric team supervisors evaluated the

obstacle, determined why it was presenting itself and determined methods to remedy the obstacle. If resources were needed outside the immediate department, appropriate personnel were approached to assist in analyzing the obstacle and brainstorming methods to remedy the problem.

Approaches taken to remedy presenting problems took into consideration the continuation of the resource library. The most feasible approach was taken to remedy the problem and analyzed for its success. If the first approach was unsuccessful, another was tried until the problem was remedied. Because the library was based on sound literature review and approval was granted from the education committee and clinical director it was expected that a pediatric resource library in the practicum setting would be successful.

Chapter Five

Strategy Employed- Action Taken and Results

The solution strategy was implemented within the expected time frame with some minor variations. The timeline of the practicum project is outlined in Appendix H. The library was initially established in a small room attached to the therapy area. During the fourth week of implementation, an inpatient, who required the use of this small room for the majority of the work day, was admitted to the hospital. This prevented the caregivers access to the room for most of the day. In order to allow access to the resource materials, they were moved onto a rolling cart which was placed within the small waiting area. Instructions for the library were placed on the waiting room table (Appendix I). Although the library was quite visible, it was observed that not all caregivers were aware of or utilized the library. During the sixth week it was felt that improved signage was necessary. A bright flyer (Appendix I) was also placed on the waiting room table. This attracted some caregivers who then asked where the library was located.

The resource library did not initially intend to have a check-out feature. In the seventh week of implementation however, a parent requested to complete a book home and another asked to bring a book home to show her husband. Both parents were allowed to take the books home and they were returned within a week. Although a check-out policy was never formally implemented, upon a caregiver's request, books and videos were allowed to be taken home after signing them out. In addition, two caregivers requested that articles be mailed to them as they

were unable to return to therapy for several weeks and wanted the information sooner. These requests were granted.

Another change from the original structure of the implementation was the inability to utilize a rehabilitation technician to assist in organizing the resource library and photocopying materials for caregivers. Although the rehabilitation technician was "available", this person was difficult to secure as he had other obligations to the department which took priority to the resource library.

Originally, Information Assessments 1 and 2 were available only in English. In order to allow all caregivers to participate, it was necessary to translate Information Assessment 1 and 2 to Spanish (Appendix J and Appendix K).

Objective 1. By the fourth week of the practicum, caregivers will have access to at least fifteen different diagnosis-related books and/or parenting books, fifteen diagnosis-specific pamphlets, a list of local and national disability-related organizations, and a list of community resources. (List of resources to be included in practicum report.)

This objective was met.

The library was stocked with many articles and books obtained by the author and already owned by the hospital, however, one of the book orders did not arrive until the sixth week of implementation because of the United Parcel Service strike. A second book order and subscription to Exceptional Parent magazine were submitted for order by the author and never arrived. It is unclear if these orders were implemented. Although some books did not arrive until the sixth week, the caregivers had access to at least fifteen different diagnosis-related and or parenting books, fifteen diagnosis-specific pamphlets, and a list of community resources. The

complete index of materials in the resource library is included in the Library Index (Appendix L).

Because of the budget allotted, $500.00, a computer was not a feasible part of the resource library. The student discussed the importance of current and vast information through the internet with administration, but monetary and phone line use were concerns. The student discovered a grant providing the practicum setting with moneys for hardware and software and access to the internet and several medical data bases. In order to qualify the practicum setting needed to provide a certain amount of space, a paid staff member ten hours a week dedicated to the computer and subscription to ten current medical and medically related journals. Space and money were again concerns, thus the resource library did not have a computer.

Between the commencement and termination of the practicum project, there was quite an unexpected change in the patient make-up at the practicum setting. Because summer vacation ended and school began, many patients were discharged to therapy in the school system. Other patients were discharged from therapy as they had achieved set goals. New patients began therapy during this time as well. Although 37 caregivers completed Information Assessment 1, only 7 of these caregivers completed Information Assessment 2 as well. These 7 caregivers were still bringing their children to the practicum setting and completed both pre and post -tests. This represents a 19 percent return rate. Not all caregivers who completed the pre-test and continued to bring their children to therapy at the culmination of the ten week implementation phase, completed the post-test.

These 7 caregivers varied in their demographic information. They represented a variety of age groups (Appendix M, Figure M1). 6 caregivers were female and the child's mother. 1

caregiver was the child's father (Appendix M, Figure M2 and M3). Caregivers race/ ethnicity in descending order were Caucasian, Hispanic, and Black (Appendix M, Figure M4). Most caregivers were married (Appendix M, Figure M5). Education levels varied with most of the caregivers receiving a high school diploma (Appendix M, Figure M6).

The caregivers had a varying number of children in the family ranging from 1-6 with an average of 2.6 (Appendix M, Figure M7). The children receiving therapy ranged in age from 20 months to 13 years old, with an average age of 6 1/2 years old (Appendix M, Figure M8). Diagnoses of these children are listed in Table N1 (Appendix N). The children had been receiving therapy from 10 months to 11 years, with an average of 46.8 months (3.9 years) of therapy (Appendix M, Figure M9). The children had been receiving therapy at the practicum setting from 3 weeks to 2 1/2 years with an average of 14.6 months (Appendix M, Figure M10).

The children received a variety of therapies including Occupational, Physical and Speech Therapies (Appendix M, Figure M11). The children received therapy from 2-4 times per week with an average of 2.5 therapy visits per week (Appendix M, Figure M12). 5 children attended school and 2 did not (Appendix M, Figure M13). Those who attended, were enrolled in a full-time program (Appendix M, Figure M14).

In order to determine if objectives 2-8 were met for these 7 caregivers, pre and post-test scores were tallied and compared.

Objective 2. By the end of the ten-week practicum, caregivers will increase the amount of information they have about their children's diagnoses as indicated by an average increase of one point on a pr/post test analysis of group data when questions 16, 17 and 81 are averaged and Information Assessment 1 (IA 1) is compared to Information Assessment 2 (IA 2).

This objective was not met.

On IA 1 (pre-test), the average of question 16, 17 and 18 was 3.81 on a scale of 1-5. On IA 2 (post-test), the average of questions 16, 17 and 18 was 4.48 (Appendix M, Figure M15). This reflected an increase of 0.67 and not an increase of one point as outlined in the objective. The prediction of one point may have been too high. In addition, the pre-test score of 3.81 is quite high and indeed higher than anticipated prior to the distribution of IA 1. It is possible that caregivers had prior knowledge through therapists and other professionals and this prior knowledge was not taken into account. Although the objective was not met, caregivers amount of information about their children's diagnosis did increase. This emphasizes that a program geared to providing education to caregivers can make a positive impact.

Objective 3. By the end of the ten-week practicum, caregivers will increase in knowledge of community resources as indicated by an increase in response on group data of three new community resources listed in question 20 when Information Assessment 1 is compared to Information Assessment 2.

This objective was not met.

Although the average response to question 19, asking how much information caregivers had about community resources, increased by 1.57 points the data requested to achieve objective 3 was not met. On IA 1 caregivers had an average score of 2.57 regarding the amount of information they had about community resources. On IA 2, they had an average score of 4.14 (Appendix M, Figure M16). The criteria to achieve this goal, however, indicated that caregivers would list three new community resources. On IA , 16 community resources were listed and on

IA 2, only 14 community resources were listed. Only 4 of the 7 caregivers completed this question. This can account for non-achievement of this objective.

Objective 4. By the end of the ten-week practicum, caregivers will increase in their information level of developmentally appropriate tasks for their children as indicated by an average increase of one point on pre/post test analysis of group data of question 22 when IA 1 is compared to IA 2.

This objective was met.

On IA 1 the average level of information on developmentally appropriate tasks was 3.57. On IA 2, the average level of information on developmentally appropriate tasks was 4.71 (Appendix M, Figure M17). This reflected an average increase of 1.14 points. This indicates that providing information to caregivers can make a positive impact on their level of information.

Objective 5. Caregivers will be able to identify three new developmental activities they have implemented with their children through the use of the resource library (question 23).

This objective was met.

A total of three new activities were listed as a result of using the resource library. Although it would have been preferable to see more activities listed, the three activities suffices in achieving objective 5. These activities are listed on Table N2 (Appendix N).

Objective 6. By the end of the ten-week practicum, caregivers will increase in feelings of comfort in dealing with and speaking to professionals as indicated by an average increase of one point on a pre/post-test analysis of group data when questions 24, 25, 26 and 27 are averaged and IA 1 is compared to IA 2.

This objective was not met.

The average of these questions on IA 1 was 3.79. The average of these questions on IA 2 was 4.47 (Appendix M, Figure M18). Although the average increased by .68 points, it did not increase by one point as indicated as criteria to achieve this objective. The pre-test score of 3.79 was higher than anticipated and did not take into account information that caregivers may have already gathered from therapists and other professionals. The increase in score does indicate that providing caregivers with information can make a positive impact on caregivers.

Objective 7. By the end of the ten-week practicum, caregivers will increase in their confidence in advocating for their children as indicated by an average increase of one point on a pre/post test analysis of group data when questions 28, 29, 30 and 31 are averaged and IA 1 is compared to IA 2.

This objective was not met.

The average response to these questions on IA 1 was 4.32 and on IA 2 the average response was 4.64 (Appendix M, Figure 19). Although the score did increase by .32 points, it did not increase by one point as indicated as criteria to achieve this objective. Again the pre-test score of 4.32 was higher than anticipated and objectives were determined prior to the completion of IA 1 by caregivers. The pre-test score did not take into account any information already gathered by caregivers prior to the implementation of the practicum project.

Objective 8. By the end of the ten-week practicum, caregivers will increase in their awareness of how to access information about their children's care as indicated by an average increase of one point on a pre/post test analysis of group data when questions 33 and 34 are averaged and IA 1 is compared to IA 2.

This objective was met.

On IA 1 the average level of awareness of how to access information about their children's care was 2.79. The average level of awareness of how to access information about their children's care on IA 2 was 3.79 (Appendix M, Figure M20). This reflects an increase of one point between pre and post-tests. The increase of one point between pre and post-tests indicate that providing caregivers with information can make a positive impact.

It was unexpected that there would be such a significant change in clientele from commencement to termination of the practicum implementation phase and only 7 caregivers would complete both pre and post-tests as indicated above. It is interesting though, to analyze all the data. To determine if Objectives 2 - 8 were met, pre- test and post test scores were tallied and compared as was done for the 7 caregivers above. A total of thirty-seven caregivers completed Information Assessment 1 (IA 1). Thirty-one caregivers completed Information Assessment 2 (IA 2). The census in the department decreased between the time IA 1 and IA 2 were distributed, reflecting the decrease in participants. Surprisingly, much of the demographic data was similar. The median age of caregivers was 31-35 years. Most caregivers were female and the child's mother. Caregivers race/ethnicity in descending order were Caucasian, Black, Hispanic and other. Most caregivers were married. Education level between the pre and post-test groups had the greatest difference. The majority of caregivers completing Information Assessment 1 attended some college with the next largest group holding college degrees. The majority of caregivers completing Information Assessment 2 had either a high school diploma or a college degree. More caregivers completing IA 1 had a college degree, and more caregivers completing IA 2 had a graduate school degree.

Caregivers in both the pre and post-tests had an average of 2.23 children. On IA 1 the number of children per caregiver ranged from 0-6 and on IA 2 the range was from 0-5. The children receiving therapeutic intervention ranged in age from 7 months to 14 years on IA 1 averaging 5.2 years old. The children receiving intervention on IA 2 ranged in age from 8 months to 15 years with an average age of 5.9 years. Diagnoses of caregiver's children varied greatly.

On IA 1, the children had been receiving therapy from 6 weeks to 11 years, with an average 26.1 months of therapy. On IA 2, the children had been receiving therapy from 2 weeks to 12 years, with an average of 34.3 months of therapy. The children on IA 1 had been receiving therapy at the practicum setting from 3 weeks to 3 years with an average of 11.6 months. The children on IA 2 had been receiving therapy at the practicum setting from 2 weeks to 3 years with an average of 14.9 months. The children on IA 1 received therapy from 1-5 times per week with an average of 2.8 times per week. The children on IA 2 received therapy from 1-4 times per week with an average of 2.2 times per week. 23 children in IA 1 attended school, 14 did not. For those that did attend school, the average was 4.4 days per week. 25 children in IA 2 attended school, 8 did not. For those that did attend school, the average was 4.8 days per week.

Objective 2 was not met.

On Information Assessment 1 (pre-test), the average of questions 16, 17 and 18 was 3.63 on a scale of 1-5, indicating the amount of information they had about their children's diagnoses. On Information Assessment 2 (post-test), the average of questions 16,17 and 18 was 4.08. This reflected and increase of .45 points and not an increase of 1 point as outlined in the objective. The prediction of an increase of 1 point may have been too high. In addition, the score of 3.63

on the pre-test was higher than anticipated and objectives were formed prior to distribution of Information Assessment 1. It is worth noting, though, that the points did increase on IA 2 when compared to IA 1.

Objective 3 was met.

On IA 1 caregivers responded with an average score of 2.51 regarding the amount of information they had on community resources. On IA 2, caregivers felt they had more information regarding community resources indicated by an average score of 3.60. On IA 1 a total of 25 community resources were listed with 38 total responses, as several of the same community resources were listed by different caregivers. Some caregivers did not respond to this question and one caregiver listed ten community resources. The average response per caregiver was one community resource. On IA 2 a total of 30 community resources were listed with 50 total responses as the same community resources were listed by several caregivers. Most caregivers responded to this question with an average response of two community resources. An additional thirteen community resources were listed on IA 2 that were not listed in IA 1. The above data indicate that objective 3 was met.

Objective 4 was not met.

On IA 1 the average level of caregiver information on developmentally appropriate tasks for their children was 3.49. On IA 2, the average level of caregiver information on developmentally appropriate tasks for their children was 4.23. There was an increase of .74 points in IA 2 when compared with IA 1. It is worth noting that the caregivers' level of information did increase although it did not increase by one point. The prediction of one point may have again been too high. In addition the score of 3.49 on the pre-test was higher than anticipated.

Objective 5 was met.

Nine caregivers responded that they did discover new developmental activities though the use of the resource library. A total of 12 newly discovered activities were listed. The discovery of twelve developmentally appropriate activities by caregivers indicates that objective 5 was met.

Objective 6 was not met.

The average of these questions on IA 1 indicating caregivers' level of comfort in dealing with and speaking to professionals was 4.04. The average of these questions on IA 2 was 4.37. Although the average response increased by .33 and not one point, it is noteworthy that the average did increase. The high response to these questions on IA 1 was unanticipated and the expectation was perhaps too high.

Objective 7 was not met.

Again responses to these questions on IA 1 indicating caregivers' level of confidence in advocating for their children was quite high. The average of the responses was 4.48 on IA 1. On IA 2, the average of the responses was 4.73. The increase in score was .25 and not 1 point as anticipated, yet there was an increase in score.

Objective 8 was met.

On IA 1 the average level of awareness of how to access information about their children's care was 2.84. The average level of awareness of how to access information about their children's care on IA 2 was 3.80. The point difference showed an increase of .96. This score most closely approached a one point increase. On the pre-test, caregivers listed a total of 16 agencies of which they were aware to assist in their child's care. On the post-test caregivers

listed a total of 21 agencies which could assist them with their child's care, indicating that the caregivers did increase in knowledge in how to access information.

The overall goal of the practicum was to increase caregivers' fund of information and enhance levels of confidence in regards to caring for their child with special needs. Scores improved in all objective categories indicating increases in caregivers' fund of information and levels of confidence. The intended goal of the practicum project was thus achieved.

Because the library did not have an official check-out policy, caregivers were given the opportunity to request materials to be photocopied. Caregivers completed a "Photocopy Request" (Appendix O) and dropped the request into a closed box. The box was checked daily and copies were returned to the caregiver within three days. A total of 22 photocopy requests were received throughout the practicum implementation. Materials requested included information on diagnoses, treatment options, behavior management, community and national resources, and parenting and sibling information.

An intention of the practicum project was to have caregivers complete a Library Use Survey (Appendix F) after each use of the Resource Library. Over the course of the ten week only 5 Library Use Surveys were completed and these were completed when the student requested the caregiver to do so. While having caregivers complete the pre-tests and post-tests, it was made clear by some through facial expressions and verbalizations, that they were not very interested in completing the questionnaires. When the rationale for their completion was explained, caregivers were more willing to complete the questionnaires. Because the Resource Library was not monitored and requests to complete the Library Use Survey were not implemented, this could account for the small amount of completed Library Use Surveys.

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Those Library Use Surveys that were completed, though, were positive in nature. All caregivers found the information easy to find. The caregivers used a variety of types of materials including books, fact sheets pamphlets and articles. Caregivers sought information on specific diagnoses, promoting child development, community resources, understanding their child's special needs and health information. All caregivers felt that a resource library was useful in the practicum sefting. Some caregiver comments included, " During therapy sessions is a good time for parents to find information without interruption from their children" and " I am really happy to have such easy access to information".

Although the Library Use Surveys were not filled out in great abundance, much feedback was received on the post test. Many caregivers reported their likes, dislikes and recommendations. The "likes" included:

- convenience of the resource library
- close proximity to the therapy area
- ease of use of the library
- helpful material
- good organization
- information in Spanish
- interesting information

One caregiver commented that it was "nice to know it's here if I need to know something", another stated, " I had questions, but didn't know what to ask".

There were quite a few dislikes as well. In order of frequency, these included:

- not enough space with tables and chairs to read quietly

- no librarian to assist in finding information
- no computer
- not enough time to use the library
- not enough information
- no information on some specific child's diagnoses
- index was somewhat confusing
- only recently finding out about the library

The literature is filled with documentation of caregivers of children with special needs requiring a great deal of information, information that is not as readily accessible as parenting the "typical child" The literature is also replete with problem solving approaches to providing these caregivers with the necessary information. "Library -based parent resource centers provide comprehensive parenting services to families, caretakers and professionals" (Cohen and Simkin, 1994, p. 11). In the practicum setting, caregivers were positive and welcomed the resource library. Based on comparison on pre-tests and post-tests, the caregivers gained in their level of information and confidence levels, two qualities needed to become better advocates for their children.

Chapter Six

Conclusion- Implications and Recommendations

The intervention utilized in this practicum project was successful in increasing the caregivers fund of knowledge and enhancing levels of confidence in regards to caring for their child with special needs as indicated by increases of scores on the post-test when compared to the pre-test. The intervention of a resource library was designed to be accessible, convenient and filled with relevant information. Although the library could not be consistently monitored, it was checked daily to ensure information was organized and available and requested information was photocopied. In addition caregivers commented to the student regarding their feelings about the resource library.

The results of the post- test and the caregiver comments suggest implications for the ongoing existence of this resource library and the establishment of future resource libraries in other settings. The original plan was to maintain the resource materials in a small room. The need to use this room for patient care took precedence over the resource library. The library was moved to a rolling cart placed in the parent waiting area. Although this did increase the resource library's visibility, caregivers preferred to have a quiet room where they could sit at a table and write information if needed. Placing the library back into the room will occur in the practicum setting when patient care and needs allows. Future resource libraries should designate a room with the sole purpose of use for a resource library/ education room.

Parents also requested a person, a librarian of sorts, to assist then in accessing information. It was noted that when the student was able to go to the waiting area and personally tell caregivers about the library and its contents, more caregivers used the library. It was also observed that caregivers who used the library once used it several times. Some caregivers used the library many times, others rarely or never used the resource library. Another observation made was that caregivers who had asked questions to therapists prior to the implementation of the resource library, and caregivers who showed more "interest" in their child tended to use the resource library with more frequency. Some caregivers may have poor reading ability or may not have as much initiative as another caregiver to just start looking through available materials. A librarian who is familiar with the library materials will be able to guide caregivers to appropriate resources based on parent's questions and concerns. It is uncertain at this time if a librarian will be funded at the practicum site, but those considering establishing a resource library should budget for a librarian's salary.

The librarian would not only help caregivers access information, the job would also include the responsibility of continuously accessing information for the library's growth based on parents' requests. Caregivers at the practicum site requested more information on a variety of topics, including their child's specific diagnosis, parenting, speech disorders and more information in general. Some of this was revealed during the practicum implementation but most was revealed through the post-test. A librarian, whose time was dedicated to the library, would have been able to follow-up on caregivers' requests. A budget would need to be established for the continuous purchase of materials for the library.

In addition to a librarian, a must for any resource library is a computer with internet capabilities and several medical and educational databases. Information changes quickly these days. New information is revealed and discovered almost daily. In order to provide up-to-date information, computer access is a necessity. After internet access is purchased, information obtained on the internet is free. In the county in which the practicum setting is located, internet access can be obtained free from the public library system. Once a facility subscribes to a database, the information is free as well. The computer can provide caregivers with much of the information requested even if that particular information was not available in the resource library. The librarian would be needed to assist caregivers in accessing information on the computer as well. Current plans for the practicum setting do not include a computer, but those considering establishment of a resource library should budget for a computer and access to the internet and relevant databases.

A feature that was used on an as requested basis was a check-out feature. This feature was not officially in place as the library was not monitored and there was a concern of loss of materials. If the library is staffed with a librarian as suggested, the materials can be appropriately checked out and monitored as to whether the books are returned. When materials are not returned in a timely manner, the librarian can then follow-up on retrieving the materials. A library can expect to incur a certain amount of loss of materials, however, monitoring the system will help to decrease loss.

Some feedback revealed the desire for informational videotapes. Many caregivers reported fatigue after a long day of work, caregiving and often both. During and at the end of the day, many did not want to read. Budgeting for videotapes would then be a necessity. In addition, a

television and video cassette recorder can be purchased for the library and placed in the corner of the library with headphones. This would enable caregivers to watch videotapes at the library when they might have time to watch without interruption while their child is in therapy. Once again, monitoring the use of the videotapes and videocassette recorder by a librarian would diminish loss and damage to the materials. Again due to budget limitations, future plans at the practicum setting do not include videotapes and videocassette recorder, but those establishing a resource library might find this an assent to their resources.

Feedback was received that the original file index was confusing. Thus a second index organizing the files by subject was developed and is included in Appendix L. Caregivers reported that the subject index was more easily understood. It is recommended that any information indexed should be easy for caregivers to access and understandable.

Making caregivers aware of the existence of the resource library will be another priority. A resource library is only useful if it is utilized. Flyers were placed on the waiting room table and the library was clearly marked and placed in the waiting area. The student did tell caregivers about the resource library. Still some parents reported they were unaware of the library's existence. Future suggestions are placing flyers in the mail to all those currently receiving therapy. Flyers should be placed in the packets caregivers receive when registering as an outpatient or an inpatient so they are informed of the resource library from the start of their intervention process at the facility.

It is recommended that future studies utilizing pre and post-test formats include a confidential manner which would track those caregivers that completed both Information Assessment 1 and

Information Assessment 2. This may be done by adding a question to Information Assessment 2 asking in the caregiver completing a pre-test.

The literature and the practicum project results find that caregivers of children with special needs require specific information. Because their lives are very busy, providing the information along one of their routine daily stops, i.e. a therapy clinic, is a benefit to these caregivers who find themselves with little free time. A facility that dedicates effort, time and money into the development of a resource library and markets this along with their other marketing tactics can set themselves apart a unique provider of therapy services- one that not only provides therapy for the child, but also recognizes the needs of the family.

The implications of the practicum project go farther than just providing families with information. The staff benefited as well. The staff has easily accessible information for their own use. The staff referred caregivers to the library to have their questions answered reducing the time therapists spent searching for information to give to the caregiver. This allows the staff to complete their work in a timely manner. This is not to imply that therapists, case managers, nurses, etc. should always refer caregivers elsewhere. There is indeed a need for one to one conversation with health-care professional to discuss the needs of the child and family. However, in those instances that caregivers can access the information on their own, the opportunity should be utilized.

Other facilities which implement a resource library will hopefully find similar positive results. In addition to the above recommendations, it is also suggested to begin planning and gathering resources at least six months prior to the resource library's opening. Time must be allotted to get placed on the agenda of various meetings, for approval of establishing new

programs, for budgets to get passed, for discovering and gathering materials and organizing the library.

The resource library will remain in the practicum setting. It is the student's intent to re-propose to the education committee the purchase of a computer. In addition, a budget will be requested to enlarge the library's holdings. It will be suggested that a rehabilitation technician, or a reliable volunteer, be given the responsibility of assisting caregivers, cataloging and monitoring the library and its materials. It is important that the "librarian" be familiar with the materials to facilitate accessing information and answering caregivers' questions. The student will request to assist in the library three hours a week to work with the "librarian" so she/he is familiar with all the materials.

The student has shared the results with her immediate supervisors and both were pleased with the results. The fact that no other therapy facility in the immediate area has a resource library for the caregivers caused them to feel that this was a unique feature of our hospital. Caregivers increasing information and confidence levels are always pleasant to hear. They were especially happy that the therapists were not as stressed by having to locate requested information and that hospital duties were completed in a more timely manner. Future implications necessitating budget increases were met with skepticism. Although they agreed with the recommendations, they were unsure all the monetary requests would be granted.

The student will present the results at a future pediatric staff meeting and to the hospital's education committee. The student also intends to submit this topic for presentation at the next American Occupational Therapy Association's Annual Conference. As an adjunct professor of Pediatrics in an Occupational Therapy Assistant program at a local college, the student stresses

the importance of including the caregivers in decisions and ensuring that caregivers are guided to the correct resources so they can be informed decision makers and advocates for their children. Other colleagues with which I have informally shared this material expressed interest in establishing a similar set-up at their facility.

The practicum setting has become more aware of caregiver's needs for information as a result of the implementation of this project. Providing information to caregivers does help them to be more confident in decisions about their child's care, provides developmentally appropriate information and allows caregivers to become better advocates for their child's needs.

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Appendix A

Staff Questionnaire on Parent Information

Staff Questionnaire on Parent Information

What type of information is asked of you by the caregivers of patients you treat?

_____

_____

How often are you asked for information by these caregivers?_____

_____

Does accessing and providing information to caregivers take time away from other necessary work duties?_____ If so, how much time per week do you provide accessing and providing information to caregivers? _____

Are there repercussions (i.e. late for next patient) and/or what other responsibilities does accessing and providing information to caregivers take you away from?_____

_____

What types of information do you provide to the caregivers of the patients you treat?_____

_____

_____

How often do you find yourself giving out this information?_____

_____

In your opinion, do you find the caregivers have a ___small
___medium
___large fund of knowledge?

On what do you base this answer? (i.e.) What do the parents do or say that gives you this information?_____

_____

In what areas do they have the most knowledge?_____

In what areas do they have the least knowledge?_____

Are you aware of how parents receive their information?_____ If so, what are their sources? _____

What are some ways you feel our facility can better provide information to caregivers?

_____

_____

Appendix B

Resource Assessment

Resource Assessment

We are in the process of improving programs. To help us serve you better, please complete this questionnaire.

1. How do you currently access information regarding your child's diagnosis and treatment options? _____

2. How do you currently access information regarding community resources?
_____

3. Do you ask therapists or case managers for information? ____ Why or why not? _____
_____

4. On a scale of 1-5, how easy is it for you to access information regarding your child and available resources?

1——2——3——4——5
very easy very difficult

5. On a scale of 1-5, how much information do you feel you have about your child's' diagnosis, prognosis and treatment options?

1——2——3——4——5
a little information a lot of information

6. On a scale of 1-5 how much information do you feel you have about community, state or national resources?

1——2——3——4——5
a little information a lot of information

7. In what type of information are you interested?

___ diagnosis
___prognosis
___treatment options
___community activities and resources
___assistive technology and equipment
___current legislative issues regarding children and families
___siblings of disabled children
___camps for your child
___toys and adaptive switches
___school information
___funding sources
___home activities for you and your child
___parenting
___children's books regarding diagnoses
___other PLEASE DESCRIBE _____
_____

8. In which manner do you prefer to obtain your information?

___reading books
___reading pamphlets
___using a computer -on-line services
___reading articles
___watching videos
___attending lectures
___other PLEASE DESCRIBE _____
_____

9. If a resource library with information were available to you while your child received therapy, would you utilize it? ___Yes
___No

Thank you for taking the time to fill out this questionnaire.
Please return this questionnaire to your therapist.

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Appendix C

Memo to Hospital Departments

To: Clinical Service Departments;
Occupational Therapy, Physical Therapy, Speech Therapy, Case Management, Nursing, Medicine, Psychology, Respiratory Therapy, Recreational Therapy and Pharmacy

From Helene Thau-Lieberman OTR/L, BCP

Re: Resource Library

Date:

A pediatric resource library is currently being developed. This resource library will be available to both patients, caregivers and staff. The purpose of the resource library is to provide patients, caregivers and staff information about but not limited to diagnosis, prognosis, treatment options, developmental and home activities, parenting issues, family and sibling issues, community activities and resources, assistive technology, legislative issues regarding families and children, schooling, special education, and funding sources. These materials can be accessed in the hospital only with no check-out option available.

I am aware that there are resources throughout this facility that can be housed in the resource library. Please look through your resources and determine if any of these are appropriate for a pediatric resource library. If there are materials that you do not wish to part with, but may be photocopied, please do. If necessary, I can assist.

Please bring these materials to the pediatric department by July 25 as cataloging must begin. Do not hesitate to bring materials after this date as new and relevant information is always needed.

If you have questions, please call Helene at x1304.

Thank you for your assistance.

Appendix D

Cover Letter for Information Assessment 1 and Information Assessment 2

Dear Parent/ Caregiver,

You are invited to participate in a project regarding a resource library. This project is conducted to fulfill a portion of the requirements to complete my Graduate Degree at Nova Southeastern University. For this project, I have developed a resource library to provide caregivers with information. The purpose of this research is to determine any changes in parental levels of information and confidence in regards to caring for their child through accessing information in a resource library. This research project will last ten weeks.

Your involvement will consist of filling out a questionnaire at the start of the ten week period and again at the end of the ten week period. The questionnaire should take fifteen minutes to complete. Participation in this study is voluntary. You are free to not participate in this study.

There are no risks associated with filling out the questionnaire, other than the inconvenience in taking the time to complete it. Your child or family member will not be denied any services on the basis of filling out these questionnaires.

You may receive no personal benefit from participation in this study. However, it is possible that you will gain new insights into your levels of information and confidence regarding the care your child. The knowledge gained by participating in this study will help determine the benefits of maintaining a resource center and continuing to provide information in this facility.

Any information obtained in this study will remain strictly confidential. Numbers, not names will be written on the questionnaires. All information will be used as group data, not individual data. Results of this study may be presented publicly or published, however, participant names will not be used.

Again, your participation in this study is voluntary and will not interfere with any services you or your child receives or will receive at this or any other facility. Refusal to participate in this study will not involve any penalty.

If you have any questions related to this study, feel free to contact the principal investigator, Helene Thau-Lieberman at 954-746-1304.

Thank you for your assistance.

Helene Thau-Lieberman OTR/L, BCP

Appendix E

Information Assessment 1

Information Assessment 1

1. What is your age group? ___18-21 ___36-40
___22-25 ___40-49
___26-30 ___50 -59
___31-35 ___60+

2. Gender ___ Male ___Female

3. Race/ Ethnicity ___Caucasian ___Hispanic ___Black ____Asian ____Other_____
specify

4. Marital Status ___single ___ married ___separated ___divorced ___widowed

5. Education level. ____ some high school ____ high school diploma
____ some college ____college degree
____graduate school/degree ____vocational school

6. Are you acquainted with a child who receives therapy at this facility? ___ Yes ___ No

7. Are you the child's: (choose one)
___Mother ____Female Guardian
___Father ____ Male Guardian
___Grandmother ____Relative (other than specified here)
___Grandfather ____Friend or family friend

8. How many children do you have? _____

9. Do you have a child/grandchild/relative with a disability? ___ If so, what is the diagnosis? _____
_____

PLEASE ANSWER THE FOLLOWING QUESTIONS WITH THE CHILD WHO HAS THE DISABILITY IN MIND.

10. What is the child's age? _____

11. For how long has the child been receiving therapy? _____

12. How long has the child received therapy at this facility? _____

13. What types of therapy does the child receive? Check all that apply.
_____ Occupational Therapy
_____ Physical Therapy
_____ Speech Therapy
_____ Psychology

14. How many time a week a week does the child receive therapy? _____

15. Does the child attend a school program? ____ If so, how many days a week? _____

16. How much information do you have about the child's disability?
1—2—3—4—5
a little information a lot of information

17. How much information do you have about the child's potential/prognosis?

1—2—3—4—5
a little information a lot of information

18. How much information do you have about treatment options for the child?

1—2—3—4—5
a little information a lot of information

19. How much information do you have about community resources?

1—2—3—4—5
a little information a lot of information

20. List the community resources of which you are aware?_____
_____

21. How much information do you have about how the service system for the child is organized?

1—2—3—4—5
a little information a lot of information

22. How much information do you have on developmentally appropriate activities for the child?

1—2—3—4—5
a little information a lot of information

23. Have you tried any activities at home? _____Name three you have used that were successful._____
_____
Name two you have used that were unsuccessful._____
_____

24. How comfortable are you asking therapists, teachers and doctors to clarify information you are given?

1—2—3—4—5
not comfortable very comfortable

25. How comfortable are you making suggestions regarding the child's care to therapists, teachers and doctors?

1—2—3—4—5
not comfortable very comfortable

26. Do you feel comfortable contacting your legislators about legislative issues that will effect the child?

1—2—3—4—5
not comfortable very comfortable

27. How comfortable are you working with agencies and professionals involved in the care of the child?

1—2—3—4—5
not comfortable very comfortable

28. How confident are you in your ability to help the child grow and develop?

1—2—3—4—5
not confident very confident

29. How confident are you in your ability to access the appropriate services for the child?

1—2—3—4—5

not confident very confident

30. How confident are you in the decisions you make for the child?

1—2—3—4—5

not confident very confident

31. How important is your opinion in deciding the care of the child?

1—2—3—4—5

not important very important

32. How important is the opinion of professionals in deciding the care of the child?

1—2—3—4—5

not important very important

33. How aware are you in ways to access information about the child's care?

1—2—3—4—5

not aware very aware

Name two? _____

34. How aware are you of agencies that may assist in the child's care?

1—2—3—4—5

not aware very aware

Name two? _____

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Appendix F

Library Use Survey

Library Use Survey

In order to better provide services, please fill out the following questionnaire. All responses are anonymous and will not effect services provided to you or your family members.

What information were you looking for in the resource center?

___Specific Diagnosis
___How to promote child development
___Community Resources
___How to understand my child's special needs
___Other-DESCRIBE_____
___How to parent my child
___Treatment options
___How to advocate for my child
___Planning for my child's future
___Technology Options
___Health Information

Were you able to find the information? ___Yes
___No

On a scale of 1-5, how difficult or easy was it to access information?

1—2—3—4—5
difficult easy

What type of materials did you use?

___Books ___Pamphlets
___Fact Sheets ___Articles

In your opinion, what is the best way to provide information to parents?

___Reading Material ___Parent Groups/ Discussion Groups
___Videos ___Television or Radio Programs
___Lectures ___Audiotape
___ Internet Access ___Other_____
specify

What types of information would be useful to you?_____
_____

On a scale of 1-5 how useful is a resource center in this setting?

1—2—3—4—5
not useful very useful

Comments_____
_____

Thank you very much for your time. Please place this survey in the designated box.

Appendix G

Information Assessment 2

Information Assessment 2

1. What is your age group? ___18-21 ___36-40
___22-25 ___40-49
___26-30 ___50 -59
___31-35 ___60+

2. Gender ___ Male ___Female

3. Race/ Ethnicity ___Caucasian ___Hispanic ___Black ____Asian ____Other _____
specify

4. Marital Status ___single ___ married ___separated ___divorced ___widowed

5. Education level. ____ some high school ____ high school diploma
____ some college ____college degree
____graduate school/degree ____vocational school

6. Are you acquainted with a child who receives therapy at this facility? ___ Yes ___ No

7. Are you the child's: (choose one)
___Mother ____Female Guardian
___Father ____ Male Guardian
___Grandmother ____Relative (other than specified here)
___Grandfather ____Friend or family friend

8. How many children do you have? _____

9. Do you have a child/grandchild/relative with a disability? ___ If so, what is the diagnosis? _____
_____

PLEASE ANSWER THE FOLLOWING QUESTIONS WITH THE CHILD WHO HAS THE DISABILITY IN MIND.

10. What is the child's age? _____

11. For how long has the child been receiving therapy? _____

12. How long has the child received therapy at this facility? _____

13. What types of therapy does the child receive? Check all that apply.
_____ Occupational Therapy
_____ Physical Therapy
_____ Speech Therapy
_____ Psychology

14. How many time a week a week does the child receive therapy? _____

15. Does the child attend a school program? ____ If so, how many days a week? _____

16. How much information do you have about the child's disability?
1—2—3—4—5
a little information a lot of information

17. How much information do you have about the child's potential/prognosis?
1—2—3—4—5
a little information a lot of information

18. How much information do you have about treatment options for the child?
1—2—3—4—5
a little information a lot of information

19. How much information do you have about community resources?

1—2—3—4—5
a little information a lot of information

20. List the community resources of which you are aware?_____
_____

21. How much information do you have about how the service system for the child is organized?
1—2—3—4—5
a little information a lot of information

22. How much information do you have on developmentally appropriate activities for the child?
1—2—3—4—5
a little information a lot of information

23. Have you tried any activities at home? _____Name three you have used that were successful._____
_____
Name two you have used that were unsuccessful._____
_____

23A. Have you discovered any new developmental activities through use of the resource library?_____

List these new activities?_____
_____

24. How comfortable are you asking therapists, teachers and doctors to clarify information you are given?

1—2—3—4—5
not comfortable very comfortable

25. How comfortable are you making suggestions regarding the child's care to therapists, teachers and doctors?
1—2—3—4—5
not comfortable very comfortable

26. Do you feel comfortable contacting your legislators about legislative issues that will effect the child?
1—2—3—4—5
not comfortable very comfortable

27. How comfortable are you working with agencies and professionals involved in the care of the child?
1—2—3—4—5
not comfortable very comfortable

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28. How confident are you in your ability to help the child grow and develop?
1—2—3—4—5
not confident very confident

29. How confident are you in your ability to access the appropriate services for the child?
1—2—3—4—5
not confident very confident

30. How confident are you in the decisions you make for the child?
1—2—3—4—5
not confident very confident

31. How important is your opinion in deciding the care of the child?
1—2—3—4—5
not important very important

32. How important is the opinion of professionals in deciding the care of the child?
1—2—3—4—5
not important very important

33. How aware are you in ways to access information about the child's care?
1—2—3—4—5
not aware very aware

Name two? _____

34. How aware are you of agencies that may assist in the child's care?
1—2—3—4—5
not aware very aware
Name two? _____

35. How often did you use the resource library? _____

36. What types of information did you use?

___ diagnosis
___ prognosis
___ treatment options
___ community activities and resources
___ assistive technology and equipment
___ current legislative issues regarding children and families
___ camps for your child
___ toys and adaptive switches
___ school information
___ funding sources
___ home activities for your child
___ parenting
___ Other- Please Describe _____
_____

37. What did you like about the resource library? _____
_____

38. What did you dislike about the resource library? _____
_____

39. What are your suggestions for improving the resource library? _____

Appendix H

Timeline

Ten week calendar plan for implementation of activities

Week 1

Monday

1. Review catalogues to determine which books will help meet information needs on caregivers based on their responses to Resource Assessments.

2. Complete purchase orders for books.

Tuesday

1. Meet with pediatric team to explain the resource library and their role in it
2. Have clinical director sign purchase orders for books.

3. Distribute memo to hospital departments (Appendix C) describing resource library and requesting materials for the resource library.

Wednesday- Friday

1. Call disability-related organizations for printed information and equipment companies for catalogues.

Week 2

Monday

1. Continue calling disability-related organizations for printed information.
2. Speak with hospital public relations coordinator to place announcement of resource center in hospital newsletter.

3. Send memo to key hospital personnel inviting them to visit resource library at its opening.

4. Place flyers on waiting room table announcing the opening of the resource library and its hours.

Monday - Friday

1. Index and catalogue materials as they arrive to the department.

2. Staff members begin telling caregivers and patients about the resource library and encouraging its use.

3. Staff members begin distributing Information Assessment 1 to caregivers.

Week 3

Monday

1. Open resource library

2. Have sign in book in resource library to track how often resource center is used.

3. Library Use Survey (Appendix F) available in resource library to be completed by those who use resource center.

Monday- Friday

1. Staff members continue distributing Information Assessment 1 to caregivers prior to their use of the resource library.

2. Collect completed Information Assessment 1 from caregivers

3. Collect Library Use Surveys daily.

Week 4

1. Resource library open at designated hours.

2. Monitor library use through sign-in book.

3. Collect Library Use Surveys daily.

4. Photocopy materials as requested by caregivers.

Week 5 -

1. Resource library open at designated hours.

2. Monitor library use through sign-in book.

3. Collect Library Use Surveys daily.

4. Photocopy materials as requested by caregivers.

5. Analyze data gathered from Information Assessment 1

Week 6

1. Resource library open at designated hours.

2. Monitor library use through sign-in book.

3. Collect Library Use Surveys daily.

4. Photocopy materials as requested by caregivers.

Week 7

1. Resource library open at designated hours.

2. Monitor library use through sign-in book.

3. Collect Library Use Surveys daily.

4. Photocopy materials as requested by caregivers.

Week 8

1. Resource library open at designated hours.

2. Monitor library use through sign-in book.

3. Collect Library Use Surveys daily.

4. Photocopy materials as requested by caregivers.

Week 9

1. Resource library open at designated hours.

2. Monitor library use through sign-in book.

3. Collect Library Use Surveys daily.

4. Photocopy materials as requested by caregivers.

Week 10

1. Resource library open at designated hours.

2. Monitor library use through sign-in book.

3. Collect Library Use Surveys daily.

4. Photocopy materials as requested by caregivers.

5. Staff distribute Information Assessment 2 to caregivers

6. Collect all of Information Assessment 2.

Appendix I

Resource Library Flyers

Pediatric Resource Library

Welcome to the Pediatric Resource Library. These guidelines are designed to make the library more accessible for you and others to.

1. Please sign in the "Sign In Book" using your initials.

2. Look through the Library Contents Book to see what resources and topics are included in the library.

3. The "Files" are located in the vertical file.

4. Binders and books are located in the cabinet.

5. Paper and pencils are provided to write down numbers and addresses as needed.

6. **Please do not take materials home.**

7. Read materials while you are in the hospital.

8. If you would like a copy of something, please write what you want on a Photocopy Request and drop the paper in the "Photocopy Request Box". Be as specific as possible. i.e. Title of article, pamphlet title, author or organization, and number from index if applicable. Please be aware that some materials cannot be copied as they are copyrighted. This box will be checked frequently. Turnaround time on requested information is within 5 days. Be sure to indicate how you can be notified after copies have been made by filling out requested information on Copy Request Form.

9. Each time you use the library **please** complete a "Library Use Survey" located in the wall pocket outside the resource library door. When completed, place the survey back in the pocket marked "Completed Surveys".

10. **Thank you.**

ANNOUNCING
THE PEDIATRIC RESOURCE LIBRARY

INFORMATION INCLUDES:

- A VARIETY OF DIAGNOSES

-BRAIN INJURY

-ACCESSIBLE TRAVEL AND VANS

-PARENTING

-CHILD DEVELOPMENT

-BOTOX

-SPECIAL EDUCATION

Appendix J

Information Assessment 1 - Spanish

Chequear Toda la Informacion 1

1. A que grupo de estas edades pertenece?

___18-21 ___36-40
___22-25 ___40-49
___26-30 ___50-59
___31-35 ___60+

2. Sexo ___Masculino ____Femenina

3. Raza/Etnica ___Blanca ___Espanola ___Negro ___Asiatico ____Otro____ especifique

4. Estado Marital ___Soltero ___Casado ___Separado ____Divorciado ___Viudo

5. Nivel de Educacion ___algo de secundaria ___graduado de secundaria
___algo de universidad ___graduado de universidad
___post grado ___escuela vocacional

6. Conoce a algun nino recibiendo terapia aqui? ___Si ___No

7. UD. es ___la Mama ___Guardian femenino
___el Papa ___Guardian masculino
___la Abuela ___Pariente (especifique_____)
___el Abuelo ___Amigo o amiga de la familia

8. Cuantos ninos tiene? _____

9. Tiene algun nino/nieto o pariente minusvalido? ___Cual es su diagnostico?_____

POR FAVOR, CONTESTE LAS SIGUIENTES PREGUNTAS ACERCA DEL NINO QUE ES MINUSVALIDO

10. Cuantos anos tiene el nino?_____

11. Cuanto tiempo ha estado recibiendo terapia? _____

12. Cuanto tiempo ha estado recibiendo terapia aqui? _____

13. Que clase de terapia recibe este nino? Marque cada uno.
___Terapia Ocupacional
___Terapia Fisica
___Terapia de Lenguage
___Sicologia

14. Cuantas veces a la semana recibe al nino terapia? _____

15. Atiende el nino un programa de colegio?_____Cuantos dias por semana?_____

16. Cuanta informacion tiene del diagnostico de su nino?
1—2—3—4—5
poca informacion mucha informacion

17. Cuanta informacion tiene de la prognosis/potencial del nino?
1—2—3—4—5
poca informacion mucha informacion

18. Cuanta informacion tiene de los tratamientos del nino?
1—2—3—4—5
poca informacion mucha informacion

19. Cuanta informacion tiene de los recursos que hay en la comunidad?
1—2—3—4—5
poca informacion mucha informacion

20. Anote los recursos de la comunidada que Ud. conoce. _____
_____

21. Cuanta informacion tiene de la orginizacion del sistema de servicios para el nino?
1—2—3—4—5
poca informacion mucha informacion

22. Cuanta informacion tiene de las actividades de desarrollo mental apropiadas para el nino?
1—2—3—4—5
poca informacion mucha informacion

23. Ha tratado alguna actividad en su hogar. Nombre tres que ha usado y ha tenido exito._____
_____
—

Nombre dos que no han tenido
exito._____
_____
___

24. Se siente bien al preguntar a los terapistas, profesores, doctores que aclaren informacion dada a Ud?

1—2—3—4—5
no si

25. Se siente bien al dar sugerencias acerca del cuidado del nino a terapistas, profesores y doctores?

1—2—3—4—5
no si

26. Se siente bien al ponerse en contacto con sus legisladores acerca del material legislativo que afectara al nino?

1—2—3—4—5
no si

27. Se siente bien trabajando con agencias y profesionales que tiene que ver con el cuidado del nino?

1—2—3—4—5
no si

28. Que confianza tiene en Ud. mismo en su abilidad para ayudar al crecimiento y desarrollo de su nino?

1—2—3—4—5
sin confianza mucha confianza

29. Que confianza tiene en Ud. mismo en su abilidad de tener acceso de servicios apropiado para su nino?

1—2—3—4—5
sin confianza mucha confianza

30. Que confianza tiene Ud. en las deciciones que hace para su nino?

1—2—3—4—5
sin confianza mucha confianza

31. Cuan importante es su opinion decidiendo el cuidado de su nino?

1—2—3—4—5
no importante muy importante

32. Cuan importante es la opinion de profecionales en su decision acerca del cuidado de su nino?

1—2—3—4—5
no importante muy importante

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33. Cuanto esta Ud. enterado de las maneras de acceso a informacion acerca del cuidado de su nino?

1—2—3—4—5

no enterado muy enterado

34. Cuanto esta Ud. enterado de las agencias que le pueden ayudar al cuidado de su nino?

1—2—3—4—5

no enterado muy enterado

Nombre dos. _____

Appendix K

Information Assessment 2- Spanish

Chequear Toda la Informacion 2

1. A que grupo de estas edades pertenece? ___18-21 ___36-40
___22-25 ___40-49
___26-30 ___50-59
___31-35 ___60+

2. Sexo ___Masculino ____Femenina

3. Raza/Etnica ___Blanca ___Espanola ___Negro ___Asiatico ____Otro____

especifique

4. Estado Marital ___Soltero ___Casado ___Separado ____Divorciado ___Viudo

5. Nivel de Educacion ___algo de secundaria ___graduado de secundaria
___algo de universidad ___graduado de universidad
___post grado ___escuela vocacional

6. Conoce a algun nino recibiendo terapia aqui? ___Si ___No

7. UD. es ___la Mama ___Guardian femenino
___el Papa ___Guardian masculino
___la Abuela ___Pariente (especifique_____)
___el Abuelo ___Amigo o amiga de la familia

8. Cuantos ninos tiene? _____

9. Tiene algun nino/nieto o pariente minusvalido? ___Cual es su diagnostico?_____

POR FAVOR, CONTESTE LAS SIGUIENTES PREGUNTAS ACERCA DEL NINO QUE ES MINUSVALIDO

10. Cuantos anos tiene el nino?_____

11. Cuanto tiempo ha estado recibiendo terapia? _____

12. Cuanto tiempo ha estado recibiendo terapia aqui? _____

13. Que clase de terapia recibe este nino? Marque cada uno.
___Terapia Ocupacional
___Terapia Fisica
___Terapia de Lenguage
___Sicologia

14. Cuantas veces a la semana recibe al nino terapia? _____

15. Atiende el nino un programa de colegio?_____Cuantos dias por semana?_____

16. Cuanta informacion tiene del diagnostico de su nino?
1—2—3—4—5
poca informacion mucha informacion

17. Cuanta informacion tiene de la prognosis/potencial del nino?
1—2—3—4—5
poca informacion mucha informacion

18. Cuanta informacion tiene de los tratamientos del nino?
1—2—3—4—5
poca informacion mucha informacion

19. Cuanta informacion tiene de los recursos que hay en la comunidad?
1—2—3—4—5
poca informacion mucha informacion

20. Anote los recursos de la comunidada que Ud. conoce. _____
_____

21. Cuanta informacion tiene de la orginizacion del sistema de servicios para el nino?
1—2—3—4—5
poca informacion mucha informacion

22. Cuanta informacion tiene de las actividades de desarrollo mental apropiadas para el nino?
1—2—3—4—5
poca informacion mucha informacion

23. Ha tratado alguna actividad en su hogar. Nombre tres que ha usado y ha tenido exito._____
_____
—

Nombre dos que no han tenido
exito._____

23A. Ha encontrado algun desarrollo de actividades por medio de los recursos de biblioteca?____
Nombre estas nueva actividades.

_____
_____
____

24. Se siente bien al preguntar a los terapistas, profesores, doctores que aclaren informacion dada a Ud?

1—2—3—4—5
no si

25. Se siente bien al dar sugerencias acerca del cuidado del nino a terapistas, profesores y doctores?

1—2—3—4—5
no si

26. Se siente bien al ponerse en contacto con sus legisladores acerca del material legislativo que afectara al nino?

1—2—3—4—5
no si

27. Se siente bien trabajando con agencias y profesionales que tiene que ver con el cuidado del nino?

1—2—3—4—5
no si

28. Que confianza tiene en Ud. mismo en su abilidad para ayudar al crecimiento y desarrollo de su nino?

1—2—3—4—5
sin confianza mucha confianza

29. Que confianza tiene en Ud. mismo en su abilidad de tener acceso de servicios apropiado para su nino?

1—2—3—4—5
sin confianza mucha confianza

30. Que confianza tiene Ud. en las deciciones que hace para su nino?

1—2—3—4—5
sin confianza mucha confianza

31. Cuan importante es su opinion en decidiendo el cuidado de su nino?

1—2—3—4—5

no importante muy importante

32. Cuan importante es la opinion de profecionales en su decision acerca de cuidado de su nino?

1—2—3—4—5

no importante muy importante

33.Cuanto esta Ud. enterado de las maneras de acceso a informacion acerca del cuidado de su nino?

1—2—3—4—5

no enterado muy enterado

34. Cuanto esta Ud. enterado de las agencias que le pueden ayudar al cuidado de su nino?

1—2—3—4—5

no enterado muy enterado

Nombre dos. _____

35. Con que frecuencia usa Ud. los recursos de su biblioteca?_____

36. Que tipo de informacion usa Ud?

___diagnostico
___prognosis
___opciones de tratamiento
___actividades y recursos de la comunidad
___tecnologia y equipo
___material actual legislativo con respecto a ninos y familias
___campamentos para su nino
___jugetes y toma corrientes adaptivos
___informacion de escuelas
___ recursos accesibles
___actividades de casas para su nino
___padres apropiados

Otro-por favor describ_____

_____

37. Que le gusta de la biblioteca de recurso?_____

_____

38. Que no le gusto de la biblioteca?_____

_____

39. Que sugerencias tiene para mejorar la biblioteca de recurso?_____

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Appendix L

Resource Library Index

SUBJECT INDEX

ADAPTIVE EQUIPMENT

- **Ankle Foot Orthosis** (Binder C, Parent Education)
- **Arm Restraints** (Binder C, Parent Education)
- **TLSO Brace** Care (Binder C, Parent Education)

ALLERGIES

- **Food Allergies** (File)
  1. The food allergy network
  2. Food allergy news
- **Latex Allergies** (File and Binder C, Parent Education)
  1. Guidelines for the management of the latex allergic patient
  2. Guidelines for the management of the latex allergic patient; Part 2
  3. Latex sensitivities: What to do after diagnosis

BEHAVIOR/PSYCHOSOCIAL ISSUES

- **Behavior Management** (File)
  1. Some ways to teach children acceptable behavior
  2. Basic principles
  3. You can control your child's behavior
  4. A bibliography of materials on behavior management in the home and community
- **Bereavement** (File)
  1. When a child dies
  2. Understanding grief...when a child dies
  3. Understanding grief
  4. When a brother or sister dies
  5. When a grandchild dies
  6. Caring for surviving children... when a child dies
  7. Principles of the compassionate friends
  8. Suggestions for the friends and relatives of the grieving survivor
  9. Resource guide
  10. Newsletter for bereaved parents and the people who care about them
- **Child Coping Strategies** (Binder C, Parent Education)
- **Coping with Disability** (File)
  1. Coping with disability related stress
- **Death of Child** (see Bereavement
- **Emotional Problems** (File)
  1. Emotional disturbance
- **Support and Information** (Binder C)

- **Fathering Special Needs Children** (Binder C, Family Support/ Info, #1)

COMMON CHILDHOOD ISSUES

- **Bet Wetting** (see Enuresis)
- **Cast Care** (Binder C, Parent Education)
- **Changing Burn Dressings** (Binder C, Parent Education)
- **Chicken Pox** (Binder C, Parent Education)
- **Child CPR** (Binder C, Parent Education)
- **Colds** (Binder C, Parent Education)
- **Enuresis** (Binder C, Parent Education)
- **Pediatric Development** (File)
  1. For parents: How your child develops birth to 5 years
- **Reflux Precautions** (Binder C, Parent Education)
- **Second Hand Smoke Dangers** (Binder C, Parent Education)
- **Taking a Temperature** (Binder C, Parent Education)
- **Vomiting** (Binder C, Parent Education)

DIAGNOSES

A

- **Achondroplasia** (Binder B, Orthopedic Conditions, #1)

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- **Agenesis of the Corpus Callosum** (File)
  1. Descriptive profile of families with children who have Agenesis of the Corpus Callosum
  2. References pertaining to Agenesis of the Corpus Callosum
  3. Callosal Agenesis: Review of Clinical, Pathological and Cytogenetic Features
  4. Situations and Syndromes Associated with Agenesis of the Corpus Callosum
  5. Matthew's Story
  6. Orono student makes grade
  7. Together we really do make a difference
  8. Parents seek to share knowledge of rare disorder
  9. Boy inching past survival to victory
  10. The Callosal Connection

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11. The Agenesis of the Corpus Callosum Directory

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- **AIDS / HIV** (File and Binder B)
  1. Questions about treatment for HIV disease
  2. HIV/AIDS prevention
  3. Testing positive for HIV
  4. Food safety advice for persons with AIDS
  5. Infections linked to AIDS
  6. Surgeon General's report to the American public on HIV Infection and AIDS
  7. Developmental abnormalities in infants and children with AIDS and AIDS-Related Complex
  8. Occupational Therapy with children who are HIV positive
  9. The role of Occupational Therapy in the multidisciplinary care of children with HIV infection

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- **Alternating Hemiplegia of Childhood** (Binder A)

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- **Amputations** (File and Binder B)
  1. National Amputation Foundation
  2. Tips for the amputee
  3. Psychological aspects of amputation
  4. The walk back
  5. Things to know about amputation and artificial limbs
  6. Association of children's prosthetic and orthotic clinics
  7. Support groups for amputees and their families
  8. Publications for parents and children

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- **Angelman Syndrome** (File and Binder A)
  1. Angelman Syndrome Foundation
  2. Angelman Syndrome- A parent's guide
  3. Facts about Angelman Syndrome
  4. Seizures in children with Angelman Syndrome

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- **Aphasia** (File)
  1. Fact sheet
  2. Guideposts for communicating
  3. Communicating with people who have aphasia; Do's and Don'ts
  4. The impact of aphasia on patients and family
  5. Special Report #1
  6. Associations and Agencies
  7. Selected readings
  8. Family adjustment to Aphasia
  9. Technology resource information sheet

10. Information on Aphasia rehabilitation
11. Aphasia and the law
12. Aphasia community groups

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- **Arthritis** (File)
  1. Arthritis Foundation services
  2. Arthritis answers

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- **Arthrogryposis** (Binder B, Orthopedic Conditions, #1)

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- **Asthma** (File)
  1. My Asthma coloring book
  2. Common triggers that can set off an Asthma attack
  3. Childhood Asthma
  4. Answers to the most often asked questions about Asthma
  5. Air pollution in your home
  6. Home control of allergies and Asthma

7. Facts about Asthma
8. Programs for children with Asthma
9. Facts about second-hand smoke
10. Your child and Asthma

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- **Ataxia- Adult onset** (File)
- **Ataxic Disorders** (Binder A)

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- **Attention Deficit/Hyperactivity Disorder** (File)

1. Attention Deficit Disorder Checklist- Elementary School
2. Attention Deficit Disorder Checklist- Middle/High School
3. Attention-Deficit/Hyperactivity Disorder
4. Attention-Deficit/ Hyperactivity Disorder: Briefing paper
5. Attention Deficit/ Hyperactivity Disorder: A guide for parents
6. Attention Deficit Disorder: The natural approach

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- **Autism** (File and Binder B)
  1. Treatment and interventions for children and youth with Autism
  2. Autism and therapeutic riding
  3. Behavioral treatment and normal educational and intellectual functioning in young Autistic children
  4. Early intervention for children with Autism
  5. What is Autism
  6. Options to meet the challenges of Autism
  7. Autism/PDD
  8. The Autism Society of America
  9. What is Autism? (booklet)

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B

- **Batten Disease** (Binder A)

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- **Birth Defects** (File)
  1. The birth defect information source
  2. ABDC products
  3. Birth defects foundation public health education materials
  4. What is ABDC?
  5. ABDC News
  6. ABDC Facts

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- **Blepharospasm** (Binder A)

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- **Brain Injury** (File)
  1. Pediatric Head Trauma: A guide for families
  2. Brain Injury: A family guide
  3. The effects of parental-sibling head injury on children in the family
  4. Brain Injury Association, Inc.
  5. Brain Injury Association of Florida
  6. Brain Injury Association of Florida: Resources
  7. Brain Injury Association State Resources- Florida
  8. Common reactions of parents whose children have special needs
  9. Sibling effects: The impact on other children in the family
  10. Brothers and sisters: Brain injury is a family affair
  11. Growing up with a brain injury
  12. Successful school re-integration: Optimizing the match of child and system
  13. School re-entry after head injury
  14. School reentry following mild traumatic brain injury: A proposed hospital to school protocol
  15. School reentry following severe traumatic brain injury; Guidelines for educational planning
  16. Secondary education for the head injured adolescent- case studies
  17. Education impact of Traumatic Brain Injury
  18. Returning the head-injured student to the educational setting
  19. Childhood head injury- effects on learning and behavior
  20. Planning for Traumatic Brain Injury: A new challenge for special education
  21. Brain Injuries and therapeutic riding

22. Some myths, facts and figures about childhood brain injuries
23. Head injury
24. Basic questions about Brain Injury and disability
25. Leisure time planning adds quality to life
26. Fundamental principles for family and friends
27. Fact sheet; Traumatic Brain Injury
28. Pediatric book list
29. About Head Injuries
30. Traumatic Brain Injury
31. Florida Brain and Spinal Cord Injury Program
32. The Brain Injury Association
33. She helps others to fight their way back
34. Brain Injury Association of Florida; Publication order form
35. Brain Injury Support Groups

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- **Brain Tumors** (File and Binder B)

1. Color me Hope
2. A resource guide for parents of children with brain or spinal cord tumors
3. Alex's Journey; The story of a child with a brain tumor
4. Coping with a brain tumor
5. A primer of Brain tumors

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- **Bronchiopulmonary Dysplasia** (File)

1. Predictors of neurodevelopmental outcome following Bronchiopulmonary Dysplasia

2. Neurodevelopmental outcome in infants with bronchiopulmonary Dysplasia
3. Poor prognosis after prolonged ventilation for Bronchiopulmonary Dysplasia

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C

- **Cancer** (File and Binder B)
  1. The Candlelighters childhood cancer foundation

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- **Cerebral Palsy** (File and Binder B)
  1. Research fact sheets
  2. Cerebral Palsy
  3. Advocacy- taking charge: How to do it
  4. About Cerebral Palsy
  5. What everyone should know about Cerebral palsy
  6. Management of Cerebral Palsy with Botulinum-A Toxin
  7. Incorporating Sensory Integration principles into treatment of children with Cerebral Palsy
  8. Berta Bobath: Assessment and treatment planning- a child with Cerebral Palsy
  9. Cerebral Palsy: Prognosis and how to judge it
  10. Cerebral Palsy- facts and figures
  11. A listing of United Cerebral Palsy affiliates in Florida
  12. Assistive Technology: A key to independence

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- **Charge Syndrome** (Binder A)

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- **Congenital Cardiac Condition** (Binder B)

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- **Cytomegalovirus** (Binder C, Parent Education)

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- **Cystic Fibrosis** (Binder B)

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D

- **Dandy Walker** Cyst (see Hydrocephalus)

- **Deafness/Hearing Impairment** (File)
  1. American Society for deaf children
  2. Deafness and hearing loss

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- **Deletion Syndromes of Chromosome 18** (Binder A)

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- **Down Syndrome** (File and Binder B)
  1. National Down Syndrome society general information packet .
  2. Down Syndrome
  3. Education research advocacy
  4. Sexuality in Down Syndrome
  5. The hearty and Down Syndrome
  6. Alzheimer's Disease and Down syndrome
  7. Endocrine conditions in Down Syndrome
  8. Speech and language skills in children and adolescents with Down Syndrome
  9. Speech and language skills in infants, toddlers and young children with Down Syndrome
  10. Life planning and Down Syndrome
  11. The neurology of Down Syndrome
  12. Perfect for us: A collection of poems for all families
  13. Down Syndrome fact sheet

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- **Dyslexia** (see Learning Disabilities)

- **Dystonia** (Binder A)

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E

- **Ehlers-Danlos Syndrome** (Binder A)

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- **Epilepsy** (File and Binder B)
  1. Epilepsy

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F

- **Familial Dysautonomia** (File)
  1. Familial Dysautonomia
  2. Familial Dysautonomia: Past, present and future
  3. The search for DYS
  4. Dysautonomia- child's booklet

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- **Familial Spastic Paraparesis** (Binder A)

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- **Fragile X Syndrome** (File)
  1. What is fragile X syndrome and why is it important
  2. Fragile X Syndrome- The basics
  3. Fragile X Syndrome facts
  4. Fragile X Syndrome- A handbook for families and professionals

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- **Freeman-Sheldon Syndrome** (Binder A)

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- **Frieberg's Disease** (Binder B, Neurological Disorders, #2)

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G

- **Gaucher's Disease** (Binder A)

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- **Guillain Barre Syndrome** (Binder B, Neurological Disorders)

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H

- **Head Injury** (see Brain Injury)

- **Hemophilia** (File)
  1. Hemophilia: Current medical management
  2. What you should know about Hemophilia
  3. Comprehensive Care for people with Hemophilia
  4. Hemophilia fact sheet
  5. Occupational Therapy and Hemophilia
  6. NHF Community: On the road to a cure

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- **Heterotrophic Ossification** (File)
  1. Heterotrophic Ossification

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- **Higher Education for the Disabled** (File)
  1. Program for the higher education of the disabled
  2. Life skills center
  3. Program for college students with learning disabilities
  4. Students with blindness or visual impairment in the college classroom
  5. The office for students with disabilities
  6. Services for students with disabilities
  7. Office for students with disabilities
  8. Learning disability services

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- **Hydrocephalus** (File and Binder C, Parent Education)

1. About Hydrocephalus
2. How Hydrocephalus develops from a Dandy Walker Cyst
3. Hydrocephalus fact sheet

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J

- **Juvenile Rheumatoid Arthritis** (Binder B, Orthopedic Conditions, #4)

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- **Klippel-Feil Syndrome** (Binder A)

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L

- **Learning Disabilities** (File)
  1. Learning Disabilities Association of Florida
  2. Learning Disabilities
  3. General information packet on learning disabilities
  4. Learning Disability... What is it?
  5. What are the early warning signs of learning disabilities
  6. When learning is a problem
  7. Suggestions for parents and teachers
  8. Social and emotional problems related to Dyslexia
  9. Your child looks perfectly normal but you suspect something is wrong
  10. Helping young children with learning disabilities achieve independence
  11. Helping adolescents with learning disabilities achieve independence
  12. Reading and learning disabilities
  13. NCLD's resource list
  14. Suggested reading list for parents
  15. The adult with a learning disability
  16. Parents of gifted/ learning disabled children
  17. College students with Learning Disability
  18. Taking the first step to sole learning disability
  19. Full inclusion of all students with learning disability in the regular education classroom
  20. How to participate in the IEP process
  21. Things go better when you know your learning disabled child's special education rights

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- **Legg-Perthes Disease** (Binder B, Orthopedic Conditions, #2)

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- **Limb-Deficiencies** (see Amputations)

M

- **Maple Syrup Urine Disease** (Binder A)

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- **Mental Retardation** (File)
  1. Introduction to Mental Retardation
  2. Mental Retardation

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- **Miscellaneous Syndromes** (File)
  1. Selected syndromes and uncommon conditions

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- **Multiple Disabilities** (File)
  1. Severe and/or multiple disabilities

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- **Multiplex Congenita** (Binder B, Orthopedic Conditions, #1)

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- **Muscular Dystrophy** (Binder A)

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O

- **Osgood-Schlatter's Disease** (Binder B, Orthopedic Conditions, #2)

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- **Osteochondrosis** (Binder B, Orthopedic Conditions, #2)

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- **Osteogenesis Imperfecta** (File and Binder A)
  1. Osteogenesis Imperfecta: the basics
  2. Caring for infants and children with Osteogenesis Imperfecta
  3. Osteogenesis Imperfecta Newsletter
  4. Genetics questions answered on Osteogenesis Imperfecta

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- **Pediatric Osteomyelitis** (Binder B, Orthopedic Conditions, #3)

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- **Pediatric Trauma** (File)
  1. When your child is seriously injured in an accident...the emotional impact on families
  2. Research training center in rehabilitation and childhood trauma
  3. Recommended readings for parents and family members on the effects of childhood injuries
  4. Childhood injury and disability book series for families

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- **Peripheral Neuropathy** (Binder B, Neurological Disorders, #1)

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- **Phenylketonuria** (File)

1. Phenylketonuria; the inborn metabolic disorder

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- **Prader-Willi Syndrome** (Binder A)

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- **Prematurity** (File)

1.Premature babies- Do they ever catch up?

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- **Proteus Syndrome** (Binder A)

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- **Psoriasis** (Binder C, Parent Education)

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- **Psoriatic Arthritis** (Binder B, Orthopedic Conditions, #4)

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- **Rasmussen's Syndrome** (File)
  1. Parent newsletter
  2. Medical treatment of Rasmussen's syndrome
  3. Progressive unilateral encephalopathy of childhood Rasmussen's Syndrome: A reappraisal
  4. Rasmussen's encephalitis in surgery for epilepsy
  5. Hemispherectomy for intractable seizures: long-term results in 17 patients followed for up to 38 years

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- **Reiter's Syndrome** (Binder B, Orthopedic Conditions, #4)

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- **Rett Syndrome** (File and Binder A)
  1. What is Rett Syndrome
  2. Rett Syndrome
  3. Mary's voice
  4. International Rett Syndrome Association order form
  5. Rett Syndrome: A view on care and management
  6. Rett Syndrome: Meeting the challenge of this gender-specific neurodevelopmental disorder
  7. Rett Syndrome: The evolving picture of a disorder of brain development
  8. Rett Syndrome information sheet
  9. Rett Syndrome: Recent clinical and biological aspects
  10. Rett Network
  11. Understanding your child with Rett Syndrome: An approach to education
  12. Rett Syndrome: Hypothesis
  13. Motor disabilities in the Rett Syndrome and physical therapy strategies
  14. Games and play in the Rett Syndrome
  15. The orthopedic management of Rett Syndrome
  16. The therapist's role in the management of girls with Rett Syndrome
  17. Switch use and the girl with Rett Syndrome
  18. Understanding, recognizing and treating Rett Syndrome

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- **Riley Day Syndrome** (see Familial Dysautonomia)

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- **Sudden Arrhythmia Death Syndrome (SADS)** (Binder B)

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- **Scleroderma** (File)
  1. About Scleroderma
  2. If you have Scleroderma...you need not feel alone
  3. Scleroderma federation affiliates

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- **Seizures** (Binder C, Parent Education)

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- **Sever's Disease** (Binder B, Orthopedic Conditions, #2)

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- **Sickle Cell Disease** (File)
  1. Sickle Cell Disease

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- **Smith-Magenis Syndrome** (Binder A)
- **Sotos Syndrome** (Binder A)
- **Spasmodic Dysphonia** (Binder A)
- **Spasmodic Torticollis** (Binder A)

- **Speech and Language Disorders** (File)
  1. Speech and language disorders
  2. Learning language
  3. Helping your patients with speech, language or swallowing disorders
  4. How does your child learn and talk
  5. Children's Play: Reflections of social competence
  6. To the parents of the non-fluent child

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- **Spina Bifida** (File and Binder B)
  1. Spina Bifida Association -Brochure for women
  2. What are good sources of folate
  3. 1997 Spina Bifida Association of America chapter list
  4. Spina Bifida
  5. Spina Bifida Association publication list

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- **Spinal Cord Injury** (File and Binder B)
  1. In touch with kids
  2. Florida Spinal Cord Injury Resource Center
  3. Your world changes with a spinal cord injury
  4. Spinal Cord association publication catalogue
  5. National Spinal Cord Association website address
  6. What is a spinal cord injury
  7. Life: National Spinal Cord Association newsletter
  8. Resources for pediatric spinal cord injury
  9. Pocket guide to federal help for individuals with disabilities
  10. Advice for the newly spinal cord injured
  11. National Spinal Cord Injury Association chapter network
  12. Choosing a spinal cord injury rehabilitation program
  13. What is a physiatrist?
  14. Why some people get better
  15. Spinal Cord Injury statistical information
  16. Tell it like it is
  17. Florida Brain and Spinal Cord Injury Program

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- **Stickler Syndrome** (Binder A)

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- **Stroke** (File)
  1. Stroke partnership
  2. Reducing risk and recognizing symptoms

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- **Tay- Sachs Disease** (File and Binder A)
  1. Tay Sachs
  2. The National Tay-Sachs and Allied Diseases Association
  3. Tay-Sachs and the Allied Disease
  4. Important information about the parent peer group program
  5. What every family should know
  6. The home care book: A parent's guide to caring for children with progressive neurological diseases

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- **Torticollis** (Binder B, Orthopedic Conditions, #5)

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- **Tourette Syndrome** (Binder A)

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- **Turner's Syndrome** (Binder A)

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- **Funding** (File)
  1. Pocket guide to federal help for individuals with disabilities
  2. Social Security disability claims
  3. Social Security Disability Insurance
  4. Sources for assistive technology funding
  5. Medipass
  6. Medicaid and you
  7. Medicaid eligibility
  8. List of Medicaid offices
  9. Food stamp program fact sheet

10. Food Stamp offices
11. Mail insurance criteria
12. Public assistance eligibility information sheet
13. Public medical assistance fact sheet
14. Medically needy fact sheet

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- **Legislation- Family and Children 1997** (File)
  1. Legislative update #1
  2. Legislative update #2
  3. Legislative update #3
  4. Legislative update #4
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  6. Legislative update #6
  7. Legislative update #7
  8. Legislative update #8
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  10. Legislative update wrap-up report

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- **Art/ Dance for the Disabled** (Binder C)
- **Camping** (File and Binder C)
- **Special Camps** (File and Binder C)
- **Special Olympics** (Binder C)
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- **Therapeutic Horseback Riding** (File and Binder C)
  1. The American Hippotherapy Association
  2. Guess what's happening next door?
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- **Winter and Summer Programs for the Disabled** (Binder C, Travel, #2)

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- **Doctors, Disabilities and the Family- Parents Guide** (See Parenting)
- **General Resources for Pediatrics** (Binder C)
- **Good Books for Children** (see Learning Young)
- **Home Health Notebook Sample** (File)
- **Insulin Administration** (Binder C, Parent Education)

- **Learning Young** (Binder C, Education, #5)
- **Moving- A Parent's Guide** (see Parenting)
- **Parenting** (File)
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  2. Planning a move: Mapping your strategy
  3. Doctor's, Disabilities and the family
  4. Raising a child who's different
  5. Parenting a child with special needs
  6. Respite Care: A gift of time
  7. The parent press
- **Pediatric Development** (File)
  1. For parents: How your child develops birth to 5 years
- **Sexuality and Disability**
  1. Sexuality education for children and youth with disability
- **Sibling Information** (File)
  1. For the love of siblings who cope with special brothers and sisters
  2. Children with disabilities: Understanding sibling issues
- **Special Kids, Special Families -Newsletter** (Binder C, Family Support. Info, #2)

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- **Support and Information** (Binder C)

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- **Bone Scan** (Binder C, Parent Education)
- **Botox** (File)
  1. Therapeutic application of Botulinum Toxin
  2. Treatment of spasticity with Botulinum Toxin
  3. Management of Cerebral Palsy with Botulinum-A Toxin
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  5. Botulinum Toxin in the management of the lower limb in Cerebral Palsy
- **CT Scan** (Binder C, Parent Education)
- **Electroencephalogram - E.E.G.** (Binder C, Parent Education)
- **Epidural** (Binder C, Parent Education)
- **Heart Surgery Care** (Binder C, Parent Education)
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- **Shunts** (see Hydrocephalus)
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- **Sutures -care of** (Binder C, Parent Education)
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- **Accident Safety** (Binder C, Family Support/ Info, #4)

- **Bike Helmets** (see Accident Safety)
- **Bicycle Safety** (File)
  1. Bicycle inspection checklist
  2. Safe street crossing- Activity booklet
  3. Bicycling is great fun- K- 3rd grade
  4. Safe bicycling- 4- 6th grade
  5. Bike basics- A guide to safe bicycling for ages 10-15
  6. Parents, buying a bike for your child
  7. Bicycles are vehicles: Florida's bicycle laws
- **Child Safety Seats** (Binder C, Travel, #1)
- **Preventable Common Injuries** (see Accident Safety and Safety-General)
- **Safety-General** (File)
  1. Seat belts save lives and reduce severity of injuries
  2. Football injuries
  3. Falls from windows
  4. Firearm injuries
  5. Injuries among Children
  6. Sports injuries on snow and ice
  7. Equipment protection
  8. Emergency first aid
  9. Kids in the know
  10. Childproofing basics
  11. Fire! Checklist for your escape plan
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  19. How to keep your child in one piece
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- **Transportation Safety** (File)
  1. Protecting your newborn
  2. Child passenger safety tips
  3. National Association of Governors Highway Safety Representatives
  4. Are you using it right (car seats)
- **Water Safety/ Drowning Precautions** (Binder C, Family Support/Info, #3)

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- **Broward County School Program Information** (see Special Education)
- **Early Intervention** (Binder C, Education, #3)
- **Early Intervention Bibliography** (Binder C, Education, #4)

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- **Higher Education for the Disabled** (File)
  1. Program for the higher education of the disabled
  2. Life skills center
  3. Program for college students with learning disabilities
  4. Students with blindness or visual impairment in the college classroom
  5. The office for students with disabilities
  6. Services for students with disabilities
  7. Office for students with disabilities
  8. Learning disability services
- **Inclusion in School** (see Special Education)
- **Learning Young** (Binder C, Education, #5)
- **Return to School** (File)
  1. When your child goes to school after an injury
- **Special Education Services** (File)
  1. The school board of Broward County, Florida -Facts
  2. The Broward County School Board, Florida
  3. The facts about Broward County Public Schools
  4. Documents required for school registration
  5. Issues on inclusion for children under age three
  6. Questions often asked about special education services
  7. Accessing programs for infants, toddlers and preschoolers with disabilities
  8. Special education and related services: Communicating through letter writing
  9. Related Services for school-aged children with disabilities
  10. The education of children and youth with special needs: What do the laws say?
  11. Common questions about inclusion
  12. Promising practices and future directions for special education
  13. What factors determine a student's eligibility for a program for specific learning disabilities
  14. What factors determine a student's eligibility for a program for autism
  15. What factors determine a student's eligibility for a program for the visually impaired
  16. What factors determine a student's eligibility for a program for the emotionally handicapped
  17. What factors determine a student's eligibility for a program for the hearing impaired
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  21. All children are special

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- **Dorsal Rhizotomy** (File)
  1. Rhizotomy orientation
  2. Dorsal Rhizotomy for children with Cerebral Palsy

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- **Technology** (File)
  1. Computer software options
  2. Finding information about assistive technology
  3. Blueprints for independence; Environmental modification
  4. Evaluating toddlers for assistive technology
  5. Assistive technology
  6. Overview of funding sources
  7. Filing for Medicaid
  8. Medicare AAC device funding exclusion to be challenged in '97

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- **CranioSacral Therapy** (File)
  1. Discover CranioSacral Therapy
  2. CranioSacral Therapy I
  3. Discover Visceral Manipulation
  4. Visceral Manipulation
  5. ShareCare Workshop
  6. Brain & Spinal Cord Dysfunction Program
  7. Post-Traumatic Stress: Facilitating Recovery
  8. Autism: Initiating developmental gains
  9. Cancer recovery: Adjunctive therapies
  10. Pain: A search for the source
  11. Intensive treatment programs
  12. The Upledger Institute, Inc. Recommended reading list
  13. Research and observations support the existence of a CranioSacral system

- **Recreation Therapy** (File)
  1. Therapeutic Recreation in pediatrics

- **Neurodevelopmental Treatment** (File)
  1. Introduction to Neurodevelopmental Treatment

- **Sensory Integration** (File)
  1. The relationship of learning problems and classroom performance to sensory integration
  2. Sensory Integration information sheet

3. Sensory Integration; A foundation for development
4. A parent's guide to understanding Sensory Integration

- **Therapeutic Horseback Riding** (File and Binder C)
  1. The American Hippotherapy Association
  2. Guess what's happening next door?
  3. Horses for the Handicapped

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- **Access-Able Travel** (Binder C, Travel, #4)
- **Access-Able Travel Organizations** (Binder C, Travel, #3)
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  1. Vans/ Adaptations
  2. The nuts and bolts of van modification
- **Transportation Safety** (File)
  1. Protecting your newborn
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Videos

Making Life Work after a Head Injury: Part 1

Making Life Work after a Head Injury: Part 2

Making Life Work after a Head Injury: Part 3

Protecting Your Newborn

Espanol

Rehaciendo la vida despues de una lesion cerebral

TEMAS EN ESPANOL

D
Desarrollo
Desorden Deficitario de la Atencion

E
Educacion Especial
El Autismo/PDD
El Retraso Mental
El Sindrome de Down

H
Hemofilia

I
Impedimentos Visuales

L
La Epilepsia
La Espina Bifida
La Paralisis Cerebral
La Sordera y la Perdida de la Capacidad Auditiva
Lesion Cerebral

P
Problemas de Aprendizaje
Problemas Emocionales

S
Seguridad del Nino
SIDA/VIH

T
Trastornos del Habla y Lenguaje
Tumor del Cerebro

Resource Binder Contents

Section 1
Florida State Resources

Section 2
Alliance for Technology Access Centers
State Assistive Technology Programs
NARIC Guide to Resources for the Americans with Disabilities Act

Section 3
National Resources for Specific Disabilities and Conditions
Agencies and Organizations
Toll Free Numbers
National Toll-Free Numbers
Disability- Related Internet Mailing Lists
URL Address List

Section 4
Parent Training and Information Centers
Parent to Parent Programs
National Fathers' Network

Section 5
National Information and Advocacy Resources
Federal and Federally- Funded Information Resources

Section 6
Early Intervention Directory
State Directors of Special Education
University Affiliated Programs

Section 7
Matching Resources

Section 8
Mental Health Resources

Section 9
Product and Service Directory
Newsletters/ Journals
National Information Center for Children and Youth with Disabilities Publications Catalog

Community Resources/ Health and Safety/ General Information

Recreational and Leisure Programs and Activities for Special Populations- Broward County

Shake-A-Leg Miami Watersports Center

Florida Diagnostic and Learning Resources System (FDLRS) Media Center

FDLRS Facts

Foster Grandparent Program

Exceptional Student Education Parent Calendar

FDLRS Exceptional Student Newsletter

Broward County Public Schools- Preschool Exceptional Student Education

Family Network on Disabilities of Broward County and Florida

Family Network on Disabilities Parent Support Group

Family Central

National Information Center for Children and Youth with Disabilities (NICHCY)

Resources for Autism

Florida Directory of Early Childhood Services

Child Find

Prekindergarten Early Intervention Program of Broward County

After School Before School Care

Broward Children's Center

The Ann Storck Center

Head Start

Home Instruction Program for Preschool Youngsters

The Infant Referral Network

Respite Service Inc.

Tender Care Center

Sunrise- Florida Facilities

Florida First Start

Easter Seal Centers of Broward County

ARC Broward County

Rehabilitation Center for Children and Adults

Head Start Parent and Child Centers

Systematic Training for Effective Parenting

Support and Training for Infants and Mothers

Family Literacy

Support Group Network

Agency Referral Phone Numbers

Shelter Numbers

Florida Alliance for Assistive Services and Technology (FAAST)

Broward County Library- Dial a Story: Technology Center

Assistive Technology Educational Center (ATEN)- South Region

Plaster Castle

Advocacy Center for Persons with Disabilities

Independent Living Tips

Safe Kids/ Safety Tips

Bike Basics

Alternative Health Care

Suggested Guidelines for Health Examinations, Screenings and Immunizations

Fast Facts on UCP's 1996 ADA Snapshot of America

Careers- Early Childhood Special Educator, Special Education Resource Teacher, Speech Language Pathologist, Adapted Physical Education Teacher, Physical Therapist

CATALOGUES

Achievement Products

Columbia

Communication Skill Builders

Community Playthings

Equipment Shop

Kapable Kids

Rifton

Smith and Nephew

Southpaw

Therapro

Therapy Skill Builders

Woodbine House

Appendix 14
Figures

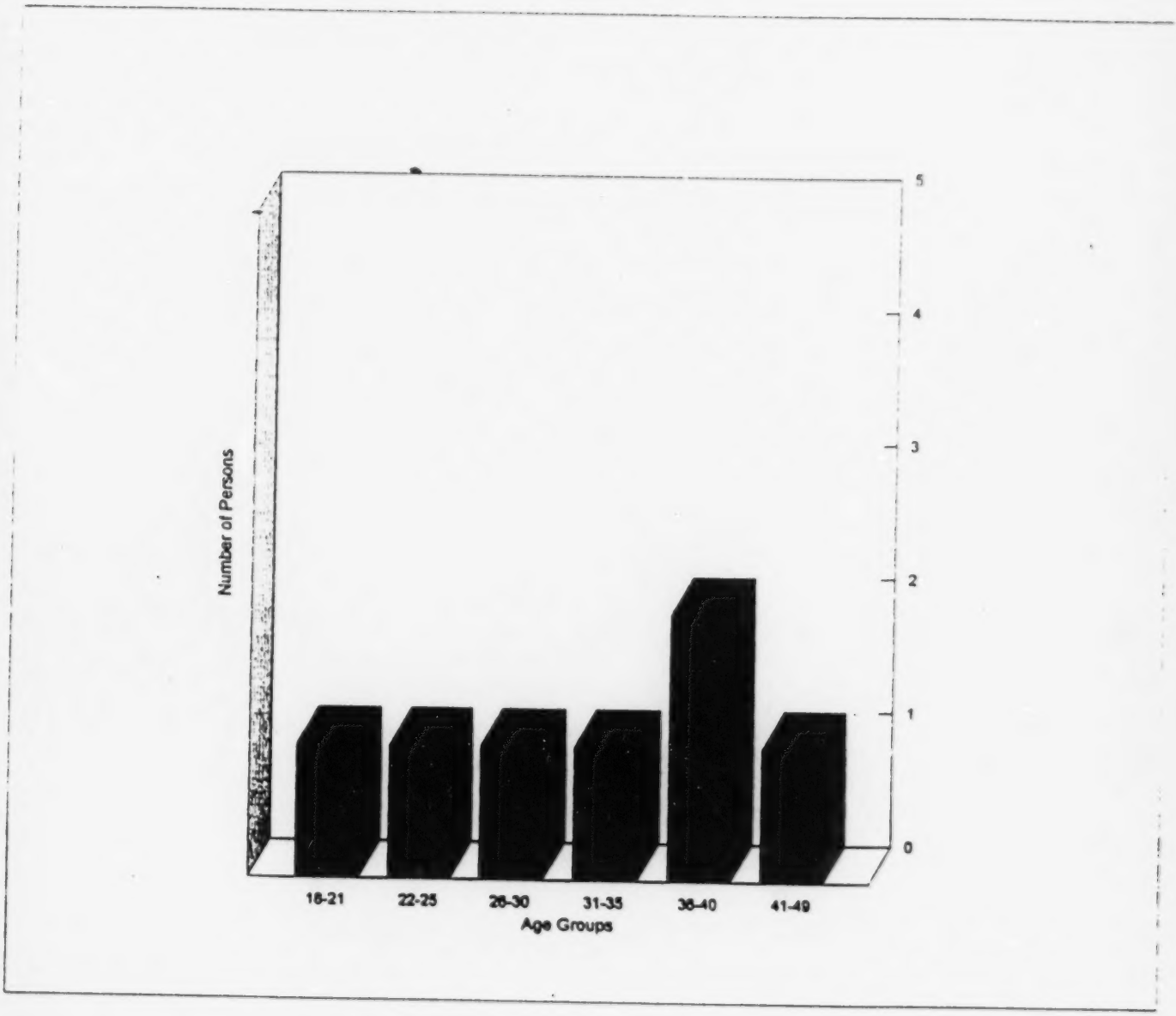


Figure M1 Age group of caregivers completing IA1 and IA2.

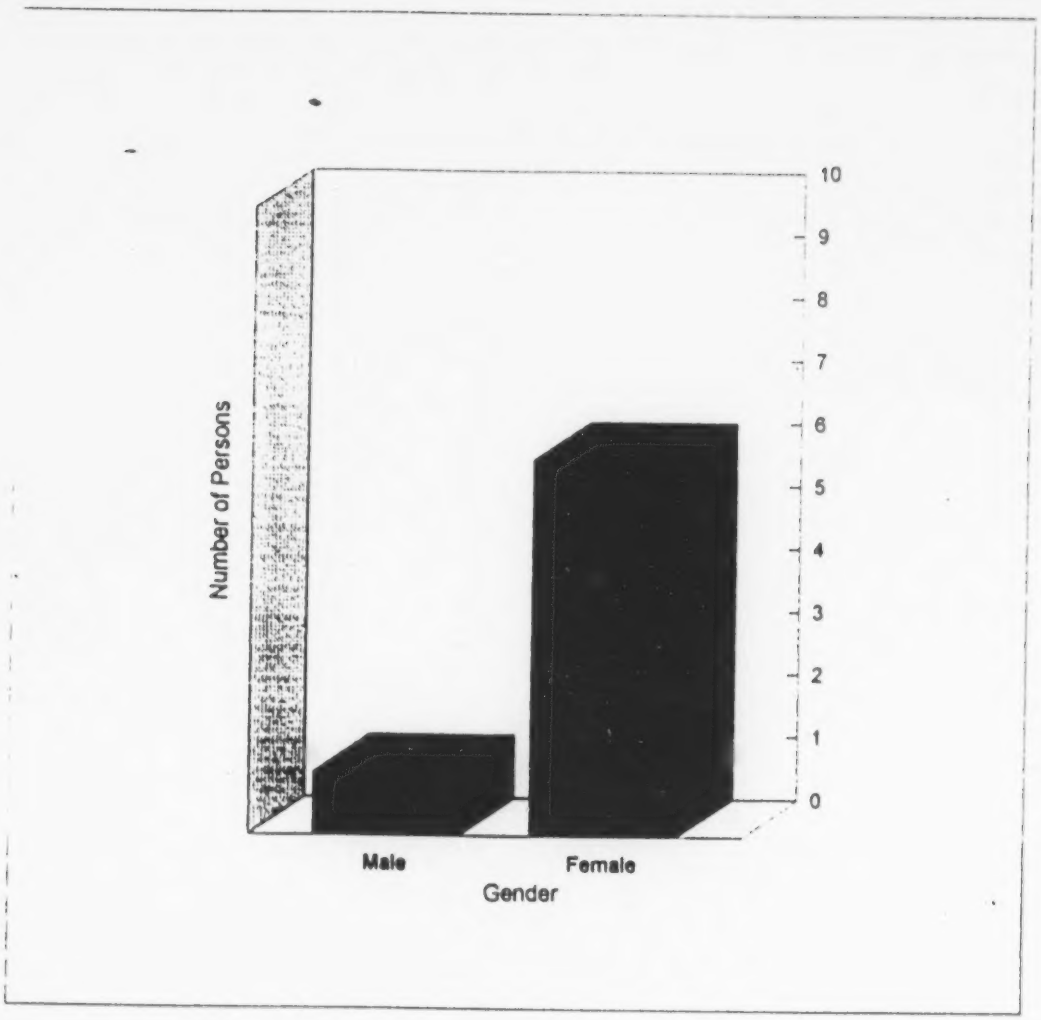


Figure M2 Gender of person completing IA1 and IA2.

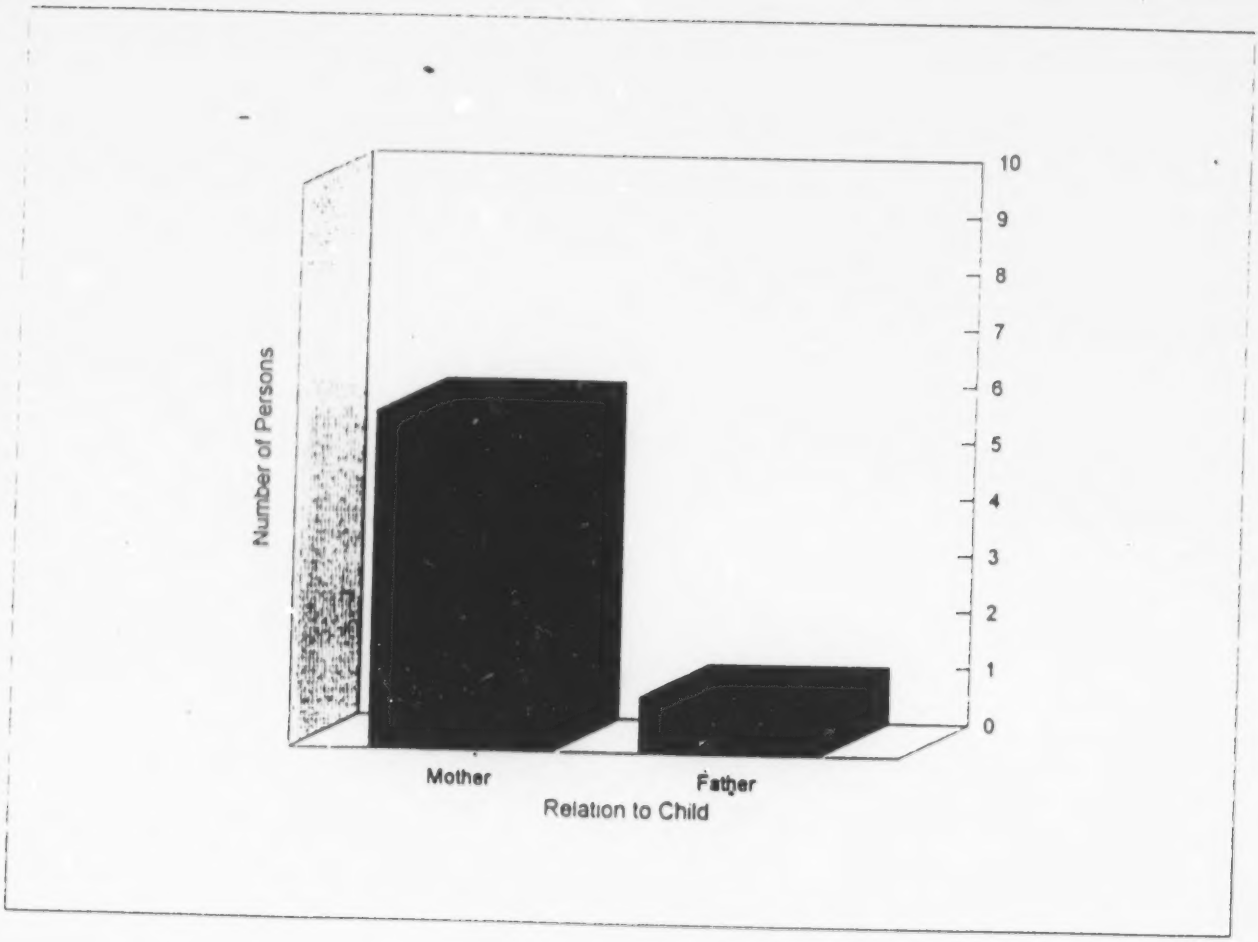


Figure M3 Relationship of the person completing IA1 and IA2 to the child receiving therapy at the practicum setting.

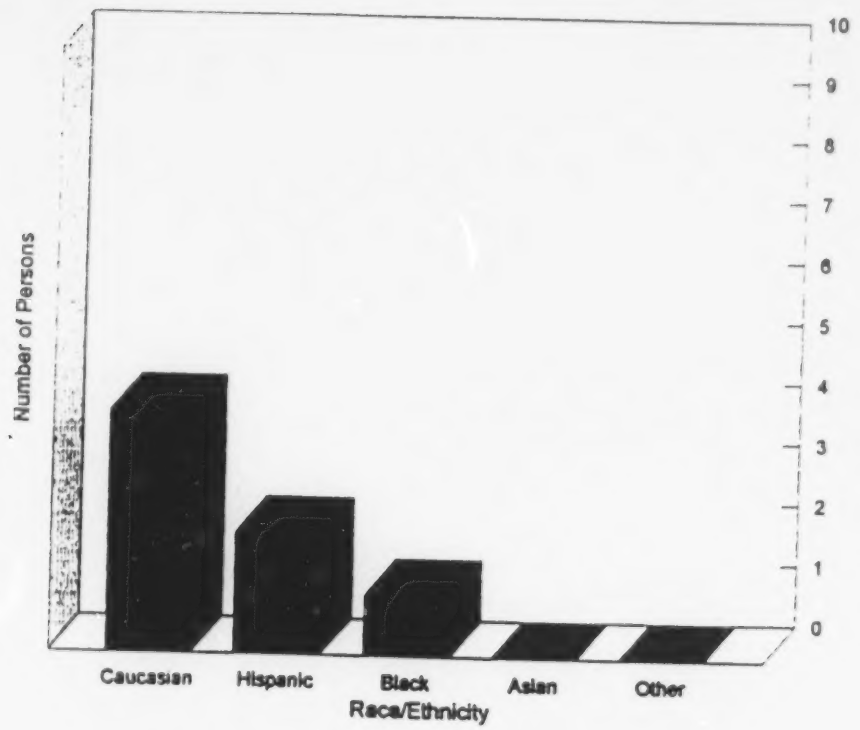


Figure M4 Race/Ethnicity of persons completing IA1 and IA2.

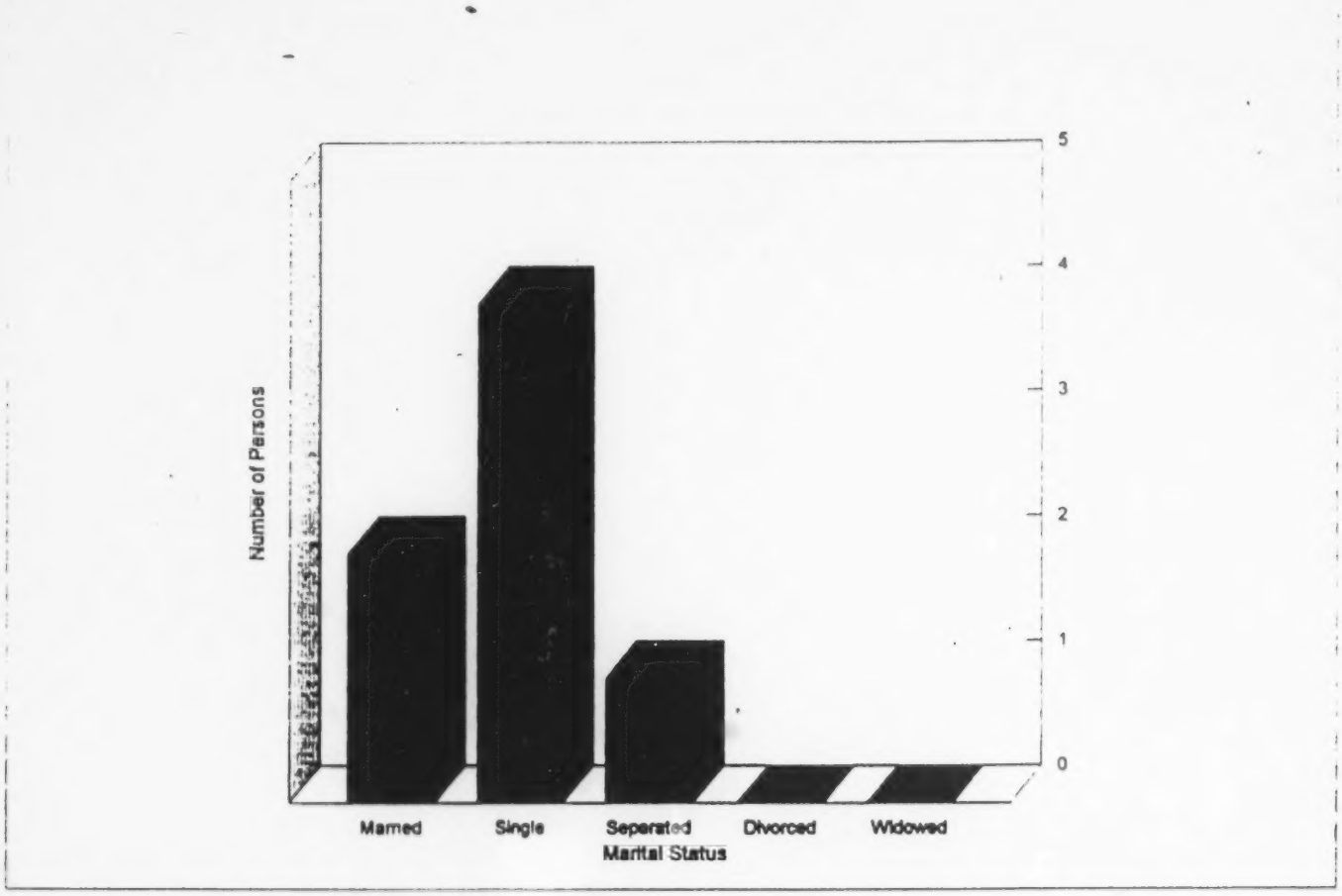


Figure M5. Marital status of persons completing IA1 and IA2.

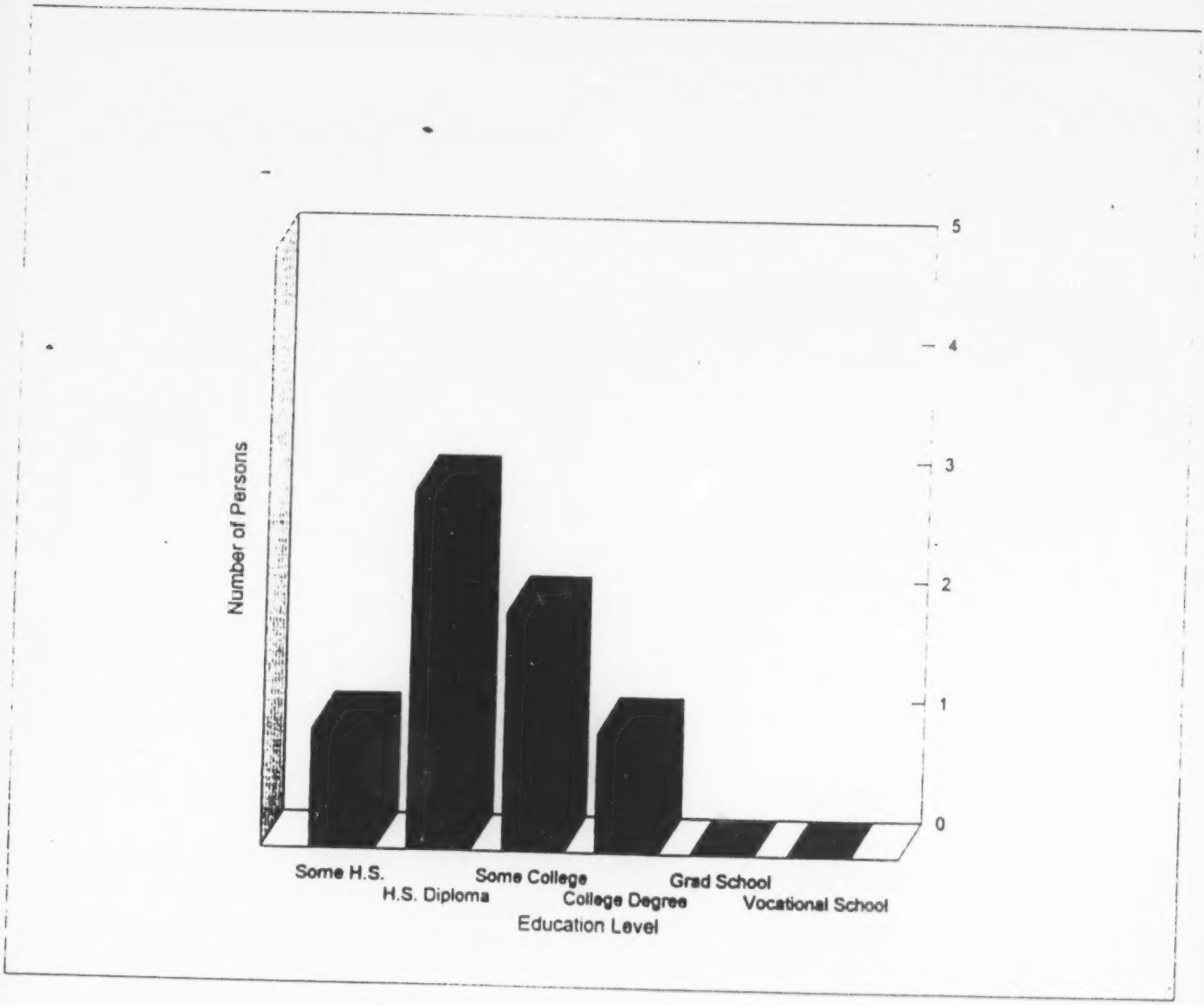


Figure M6 Education level of persons completing IA 1 and IA2.

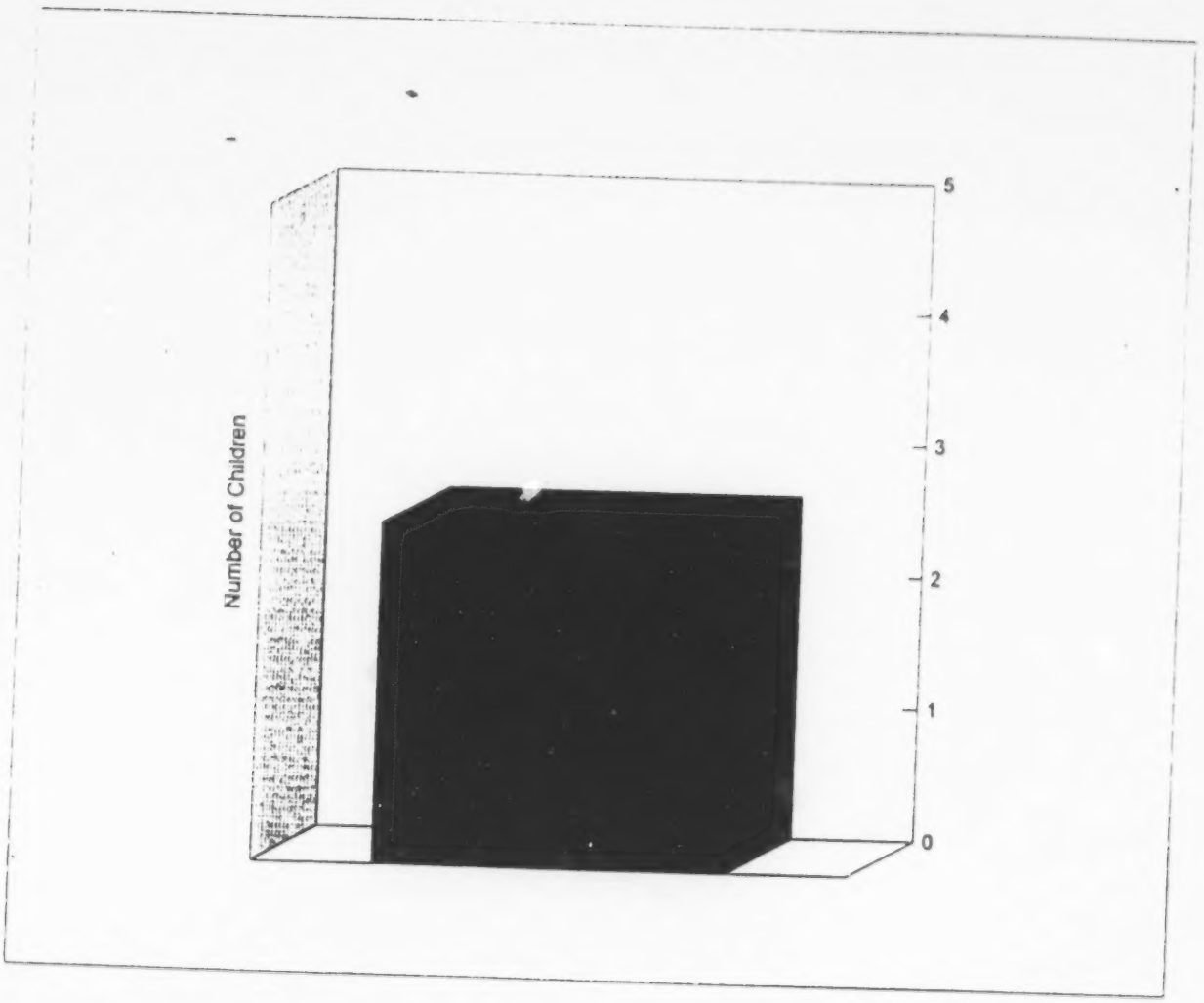


Figure M7. Average number of children persons completing IA1 and IA2 have 2.6.

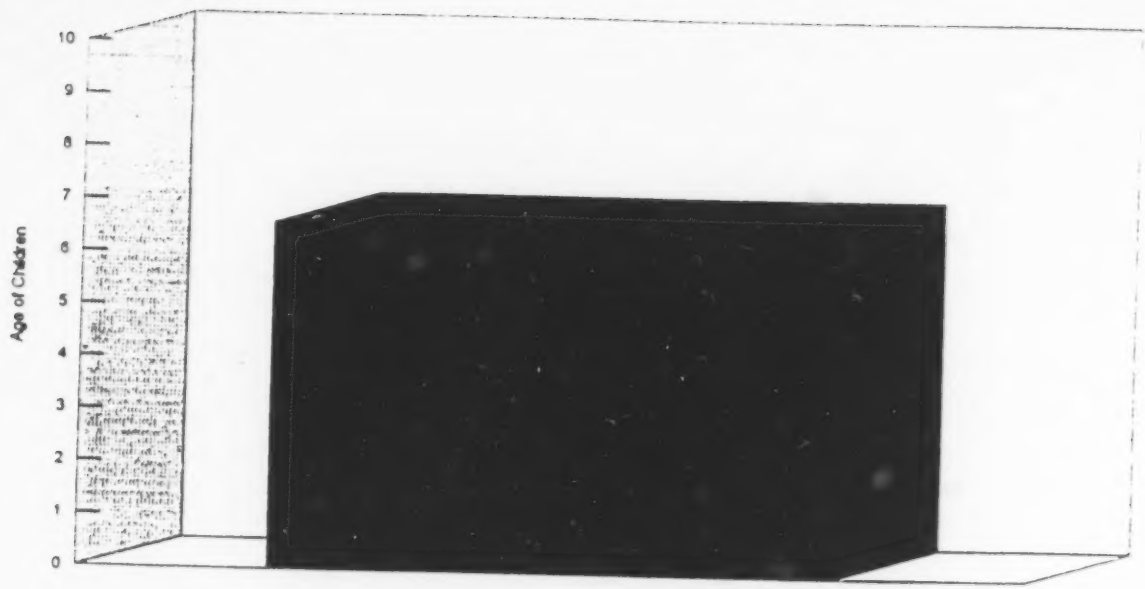


Figure M8. Average age of child with disability for which IA1 and IA2 are being completed is 6 6 years old.

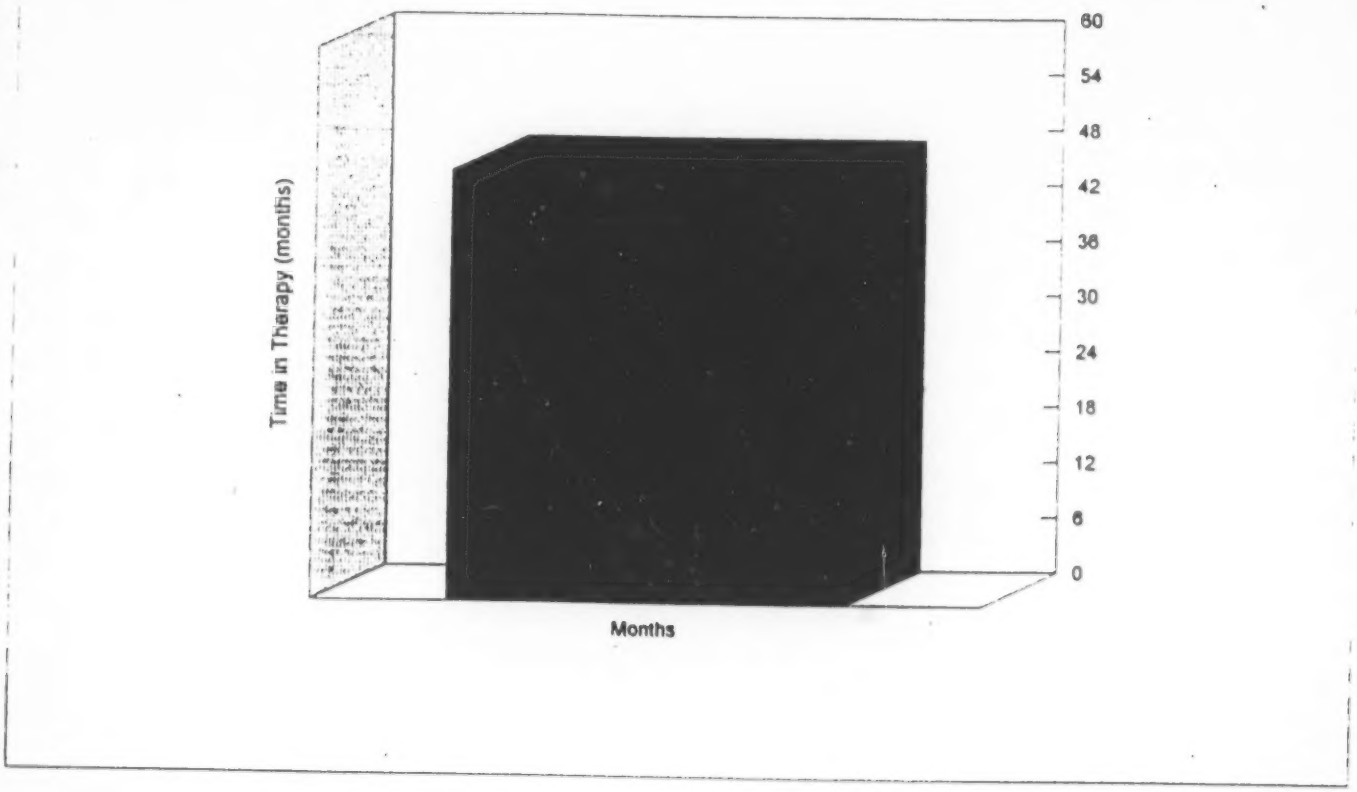


Figure M9. Average length of time child has been receiving therapeutic intervention is 46.8 months.

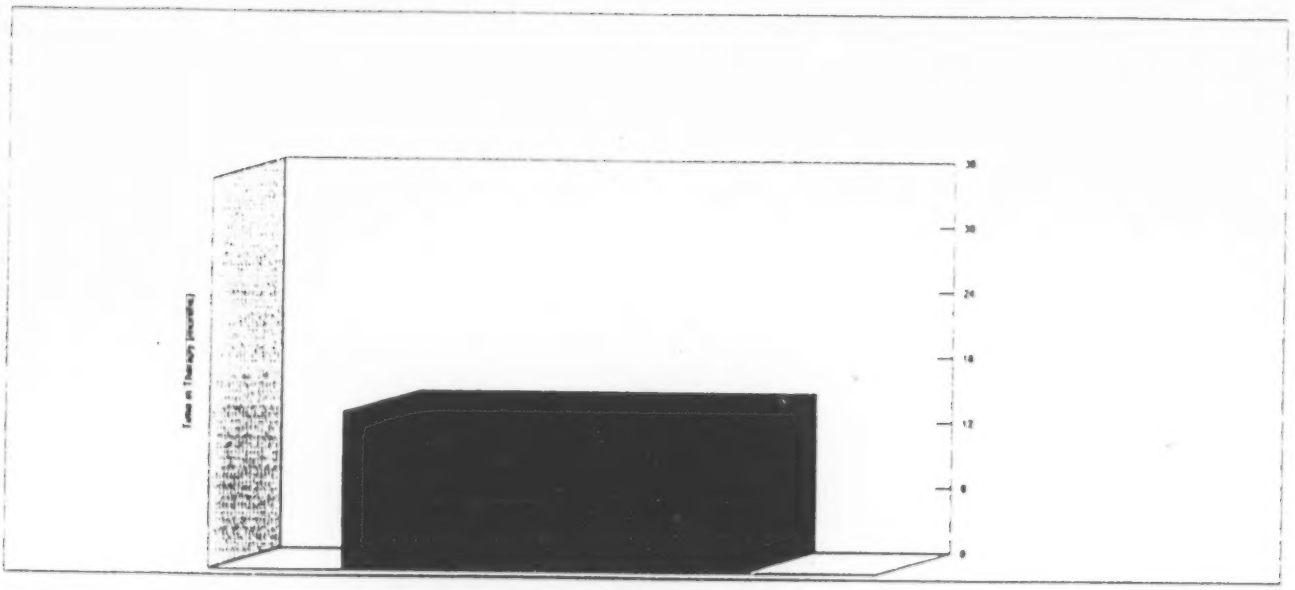


Figure M10. Average amount of time child has received therapy at the practicum setting, is 14.8 months.

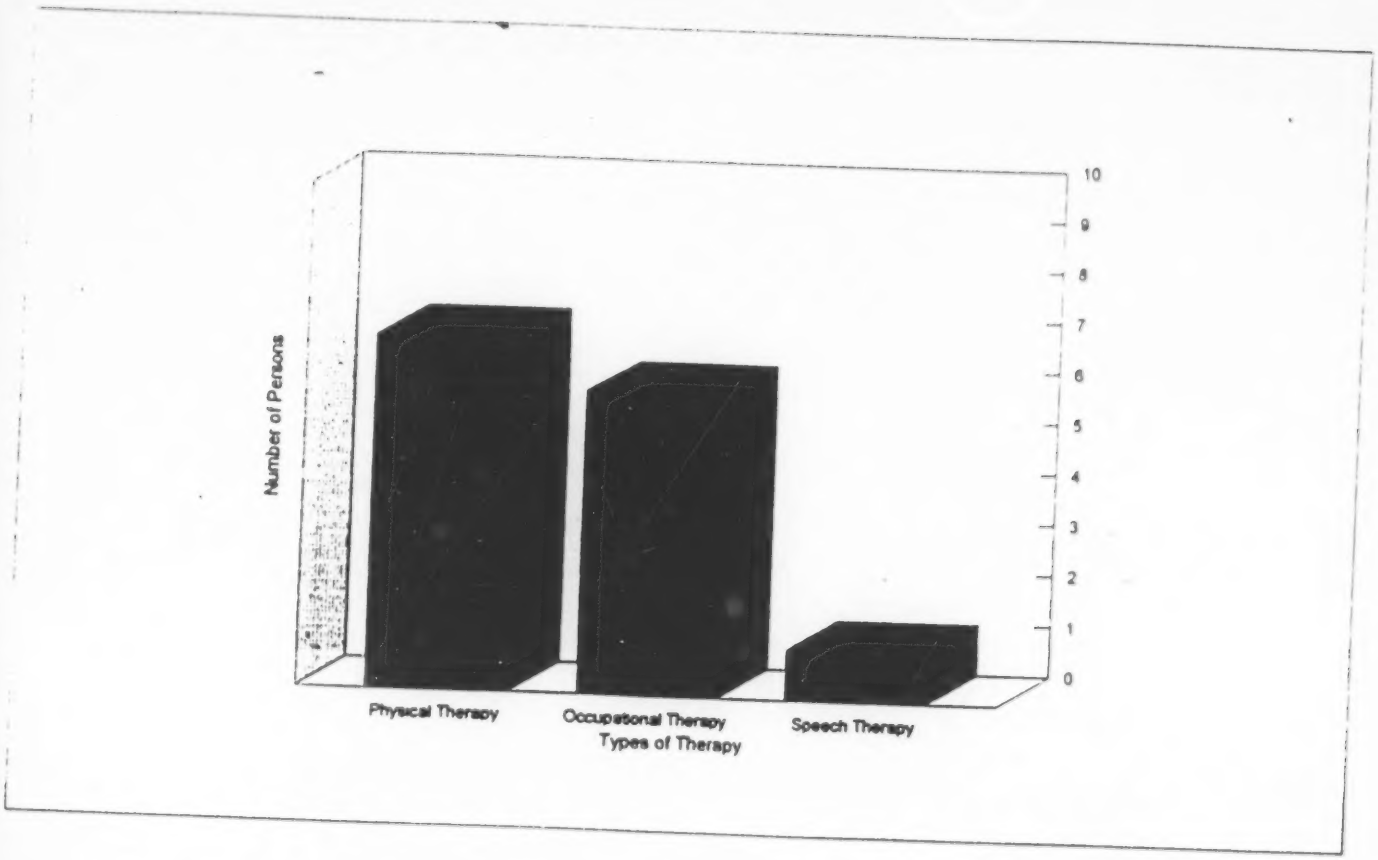
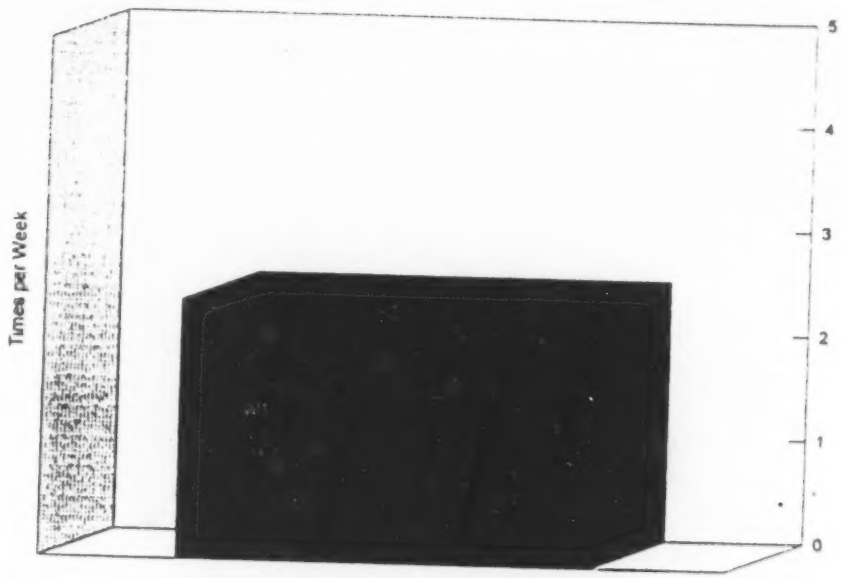


Figure M11. Types of therapy child currently receives at practicum setting.



Figures M12. Frequency of times child receives therapy

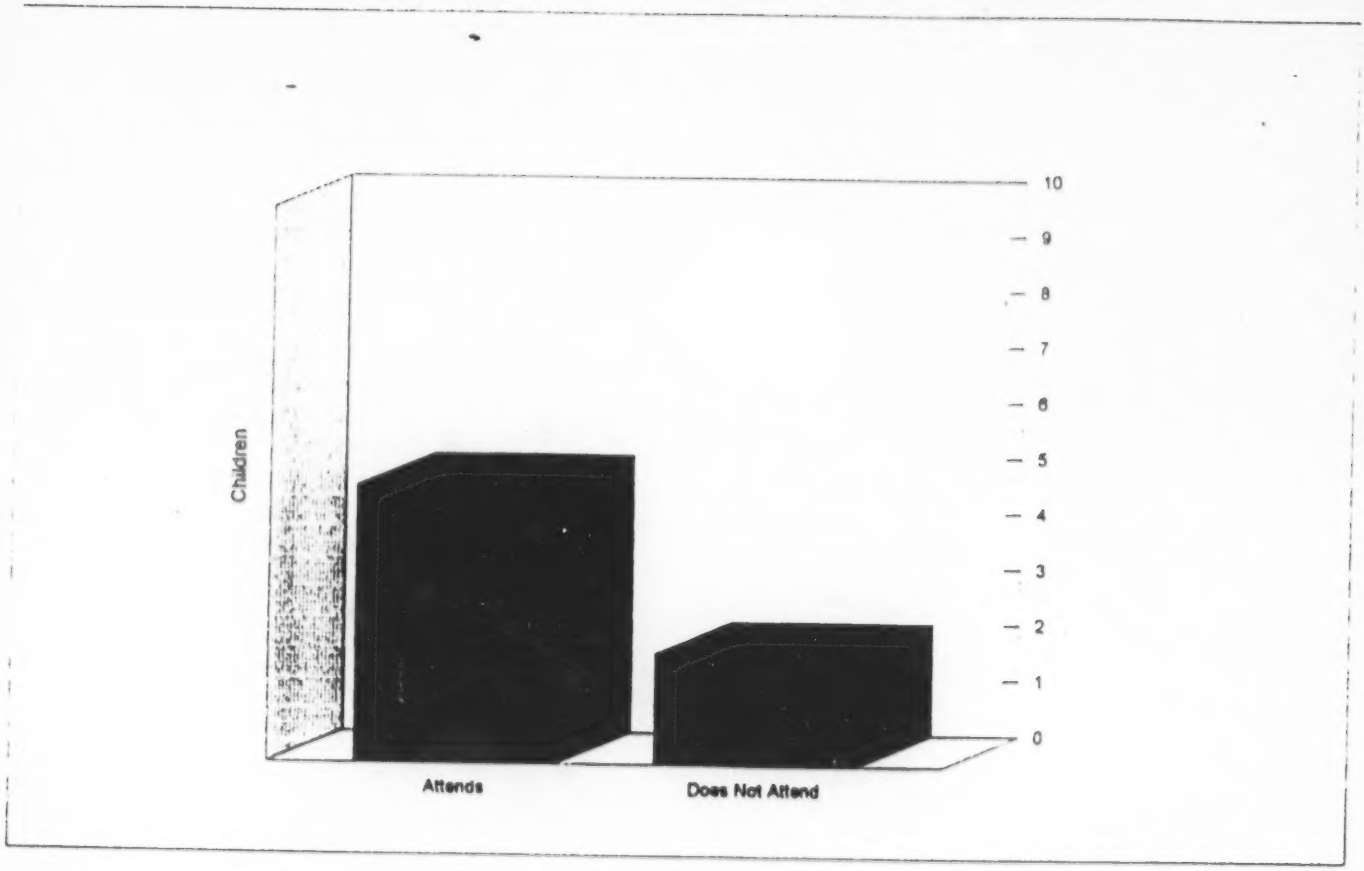


Figure M13. Number of children who attend and do not attend a school program.

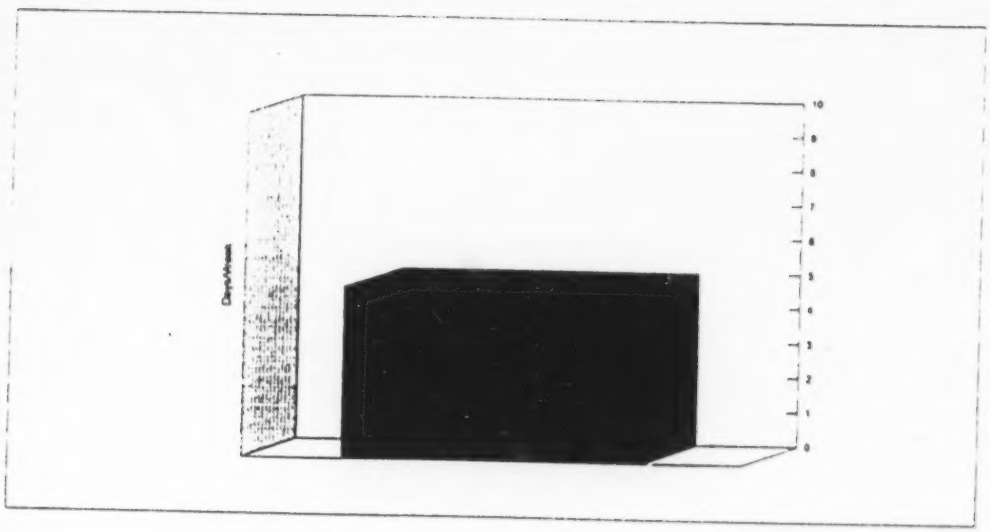


Figure M14. Frequency of child's attendance in a school program.

Caregiver's Information Regarding Child's Diagnosis

	(A1	(A2
Average Response	3.81	4.48

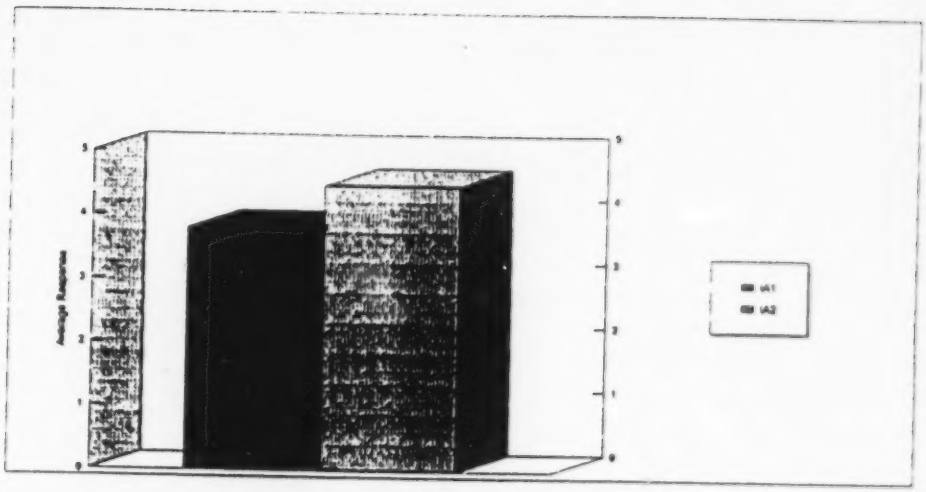


Figure M15. Average response of caregivers of amount of information they have regarding their child's diagnosis.

Caregiver's Knowledge of Community Resources

	IA1	IA2
Average Response	2.37	4.14

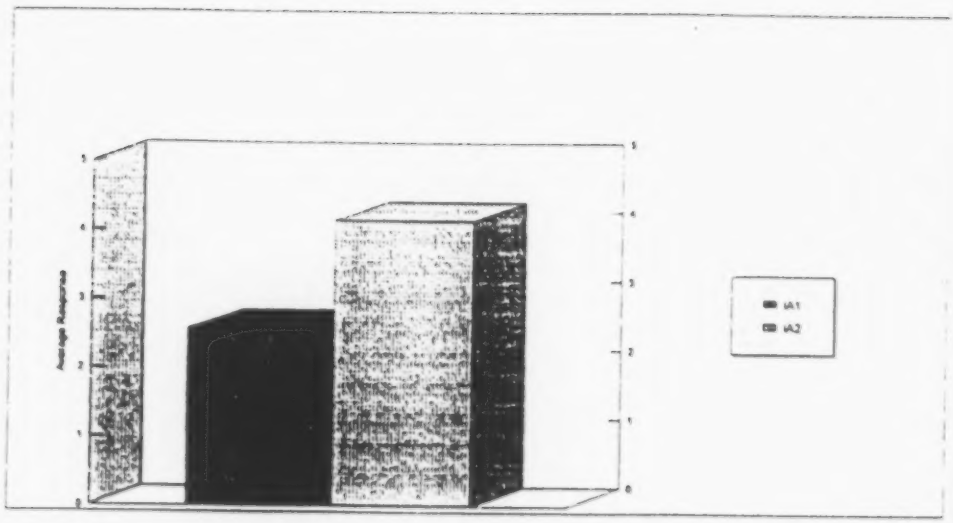


Figure M18. Average response of amount of caregiver knowledge of community resources.

Level of Information of Developmentally Appropriate Activities

	IA1	IA2
Average Response	3.37	4.71

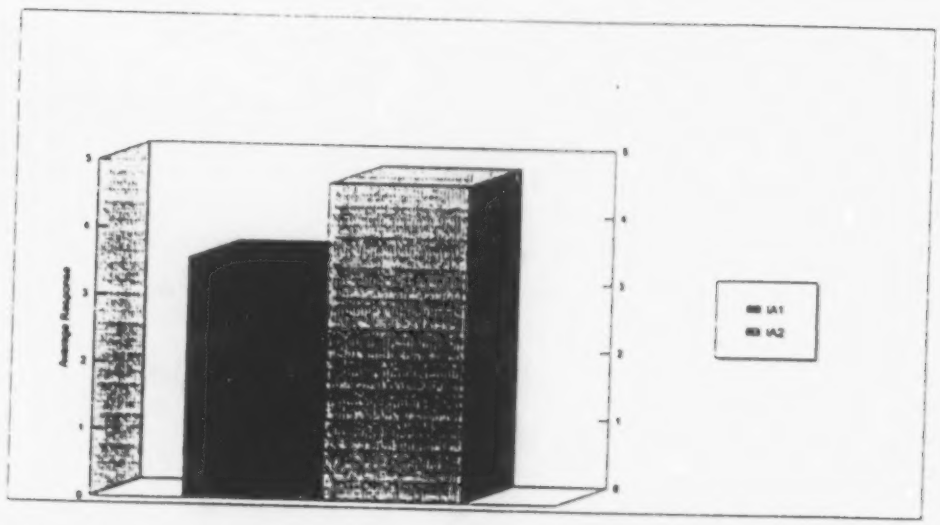


Figure M12. Average response of caregivers of the level of information they have about developmentally appropriate activities for the child.

...el of Caregiver's Comfort

	IA1	IA2
Average Response	3.79	4.47

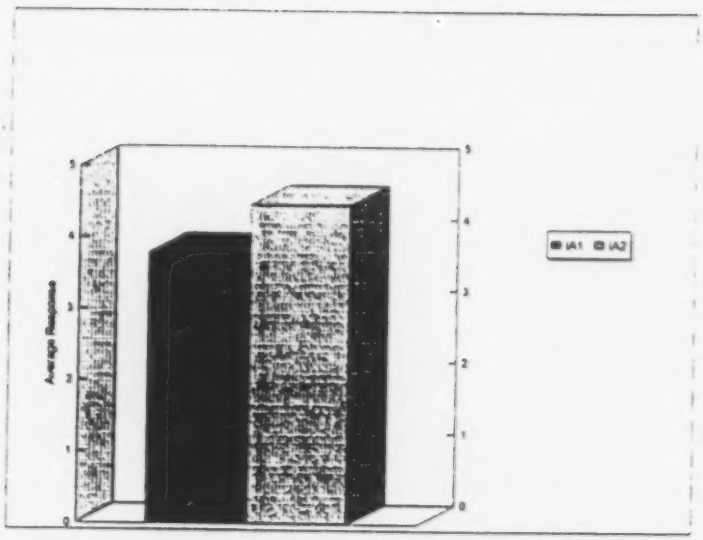


Figure 18. Average response of caregivers of the level of their comfort in dealing with professionals.

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Level of Caregiver's Confidence

	IA1	IA2
Average Response	4.32	4.64

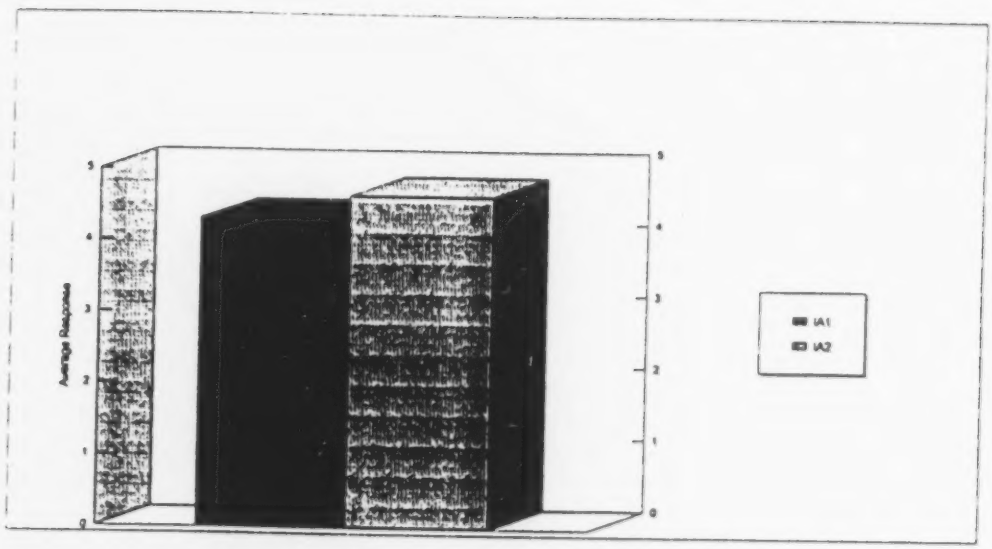

Figure M18. Average response of caregiver's level of confidence in advocating for their child.

Level of Caregiver's Awareness of Accessing Information

	IA1	IA2
Average Response	2.79	3.6

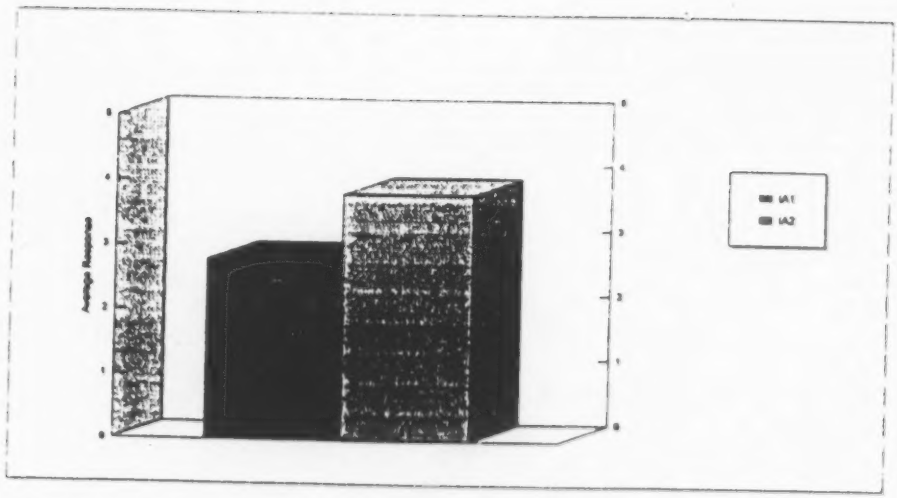

Figure M20. Average response of caregiver's level of awareness of how to access information about their child's care.

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Appendix N
Tables

TABLE N1

List of Children's Diagnoses

Brain Tumor	1
Cerebral Palsy	3
Gaucher's Disease	1
Noonan Syndrome	1
Spina Bifida	1

TABLE N2

Developmental Activities Discovered Through Use of the Resource Library:

1 Exercise on large ball
2 Use play dough for finger extension
3 Use bubbles for arm extension

Appendix O

Photocopy Request Forms

PHOTOCOPY REQUEST
Please be as specific as possible

Name_____

Phone_____

Article/Pamphlet Title_____
_____

Number from index (if applicable)
_____

Organization_____
_____

Author_____

Pages_____
Place in Photocopy Request Box

PHOTOCOPY REQUEST
Please be as specific as possible

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Phone_____

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